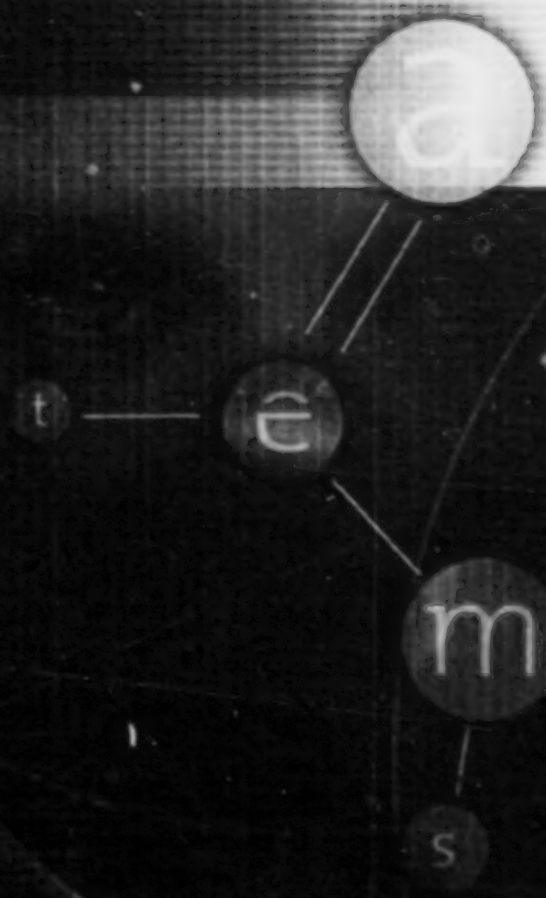
Hospital Technology at Home

Portable Oxygen Therapy in COPD



AGENCE D'ÉVALUATION DES TECHNOLOGIES
ET DES MODES D'INTERVENTION EN SANTÉ

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Hospital Technology at Home

Portable Oxygen Therapy in COPD

Report prepared for AETMIS
by Susan Law and Pascale Lehoux

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MISSION

The mission of the *Agence d'évaluation des technologies et des modes d'intervention en santé* (AETMIS) is to contribute to improving the Québec health-care system and to participate in the implementation of the Québec government's scientific policy. To accomplish this, the Agency advises and supports the Minister of Health and Social Services as well as the decision-makers in the health care system, in matters concerning the assessment of health services and technologies. The Agency makes recommendations based on scientific reports assessing the introduction, diffusion and use of health technologies, including technical aids for disabled persons, as well as the modes of providing and organizing services. The assessments take into account many factors, such as efficacy, safety and efficiency, as well as ethical, social, organizational and economic implications.

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FOREWORD

HOSPITAL TECHNOLOGY AT HOME: PORTABLE OXYGEN THERAPY IN COPD

People with chronic obstructive pulmonary disease (COPD) associated with moderate to severe hypoxaemia need long-term oxygen therapy for between 15 and 24 hours a day. Long-term oxygen therapy (LTOT) has proven to be an effective and cost-effective treatment that contributes to increasing patients' life expectancy. Introduced in the 1980s, portable oxygen systems for home use were designed to help patients comply with their prescribed treatment (i.e., dose and daily hours of use) and to improve their quality of life. The use of this equipment spread throughout the world even before solid scientific evidence had been obtained about its benefits for patients and its cost implications.

Québec's *Ministère de la Santé et des Services sociaux* (MSSS) therefore asked the *Agence d'évaluation des techniques et modes d'intervention en santé* (AETMIS) to summarize the available scientific evidence about the efficacy, safety, cost effectiveness and use of portable oxygen equipment and to evaluate its social, legal and ethical implications.

There is very limited evidence about the clinical efficacy or cost effectiveness of portable oxygen therapy. To date, only one controlled trial (completed in Québec in 2003) has been conducted with these issues in mind. According to that study, portable oxygen equipment apparently offers no benefits in terms of quality of life, compliance with treatment or exercise tolerance. It should be pointed out, however, that the sample size in this trial was too small to generalize the results to all patients.

Although the indications for long-term oxygen therapy are generally well recognized, there are no commonly accepted clinical or social indicators for prescribing portable oxygen therapy. Both the utilization of portable systems and the organizational models for health-care delivery vary considerably from one country to the next and even from one region to the next. There are no reliable data on the number of patients who actually use or who might benefit from using portable oxygen equipment. There are also widely differing views among professionals and the public on what constitutes appropriate access to portable oxygen therapy.

In light of these findings, AETMIS recommends that the MSSS should 1) define indications for each type of portable oxygen equipment; 2) develop a standardized assessment tool and standard procedures for the prescription and coverage of portable oxygen equipment; 3) set up the infrastructure for a coherent home oxygen therapy program that would include portable oxygen equipment; and 4) consider establishing a central patient registry. The MSSS is also encouraged to work in partnership with health professionals and research groups to implement a care program that is effective, efficient and fair for all patients requiring home oxygen therapy in Québec.

In submitting this report, AETMIS hopes to provide decision makers in Québec with the information they need to guide their policies and actions with respect to portable oxygen therapy.

Dr. Luc Deschênes
Chairman and Chief Executive Officer

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Any criticisms or errors remain the responsibility of the authors.

EXECUTIVE SUMMARY

Given the results of clinical trials conducted in the 1980s, long-term oxygen therapy (LTOT) has been proven to be an effective and cost-effective treatment for chronic obstructive pulmonary disease (COPD) with hypoxaemia. Oxygen therapy has been shown to increase the life expectancy of patients with moderate to severe hypoxaemia ($\leq$ 55 mm Hg saturation level) who receive oxygen from between 15 and 24 hours a day. Clinical trial results regarding the impact of LTOT on patients' quality of life, however, are inconclusive and difficult to interpret, owing to disease progression and problems associated with therapeutic compliance on the part of both health professionals and patients. Indications for long-term oxygen therapy are based on the criteria that were established for these trials and these criteria have since been adopted almost universally. Introduced in the 1980s, portable oxygen systems for home use were designed to increase patients' compliance with treatment and to improve their quality of life. The use of portable oxygen therapy spread throughout the world even before solid scientific evidence had been obtained about its benefits and cost implications.

The objectives of this report are the following: 1) to summarize published data about *a*) the effectiveness and use of portable oxygen therapy in the treatment of patients with COPD associated with severe hypoxaemia, *b*) different health-care organization models, and *c*) the cost effectiveness and quality of the care provided to these patients; and to review the psychosocial, legal and ethical implications involved in the delivery of oxygen therapy services; 2) to present a broad outline of service delivery in Québec with respect to the different types of oxygen systems available and the questions they raise; 3) to present a comparative analysis of the two home-oxygen programs in Canada that have adopted LTOT organization and service-delivery models known to be efficient and effective (Ontario and Alberta); and 4) to draw conclusions and make recommendations serving to guide the development of policies and practices, and to direct research in Québec.

Patients who require LTOT are typically over the age of 65. They are people who have smoked most of their lives and are limited in their daily activities because of the restrictions imposed by severe COPD. They have a life expectancy of approximately five years. A large minority of patients on LTOT continue to smoke. Problems related to patients' noncompliance with prescribed LTOT and portable therapy are well documented. It is also known that many health professionals fail to comply with established guidelines for LTOT.

The use of portable oxygen therapy as a component of LTOT is highly variable from one region to the next and from one country to the next, which is likely the result of two factors. First, health professionals do not have conclusive scientific evidence to make informed decisions about patient selection and therapeutic prescription. Second, there are widely differing beliefs concerning the potential benefits of portable oxygen therapy in terms of survival and quality of life. Portable systems were introduced with the intent to increase patients' mobility and ability to participate in activities outside the home, which would apparently contribute to increasing their compliance with treatment. This would in turn improve their life expectancy and quality of life.

While it has been clearly shown that the use of LTOT prolongs the lives of patients with COPD, there is limited published evidence regarding the costs and benefits of portable oxygen therapy. Oxygen therapy (with pharmacotherapy) is one of the largest cost components in the management of severe COPD with hypoxaemia, and portable oxygen therapy is commonly considered an expensive part of LTOT even though there is little information on its actual marginal costs. Whereas the criteria for prescribing LTOT are almost universally accepted, none exist for portable oxygen therapy. The United States

and the United Kingdom, however, have adopted some guidelines. The very first controlled trial to assess the costs and benefits of portable oxygen therapy was conducted at Hôpital Laval in Québec and completed in the fall of 2003. Preliminary results seem to indicate that portable oxygen equipment does not improve patients' quality of life, compliance with treatment or exercise tolerance. The researchers conclude that portable oxygen therapy should not be prescribed routinely to all oxygen-dependent patients with COPD. Nevertheless, it is doubtful whether these findings can be generalized to all patients, given that the sample size was very small (n=22) and that the researchers had difficulty recruiting patients for this trial.

In Québec, the organization and delivery of home oxygen therapy has varied significantly from one region to the next since 1998 when the services offered by the *Office des personnes handicapées du Québec* (OPHQ) were decentralized. These services are now provided at various levels. Some are regionally centralized, while others are based at a hospital or CLSC, when they are not subcontracted outright to oxygen-equipment suppliers. No data have ever been systematically gathered on the use, cost, health outcomes or quality of care, permitting an analysis of the delivery of home oxygen therapy services. Reported use of portable oxygen therapy also varies widely, but there are no precise figures available. Coverage of portable systems is complex and inconsistent across the province. Most patients with COPD who are eligible for long-term oxygen therapy do not have private insurance.

Many of the people we interviewed stated that fewer people use portable systems in Québec than in other provinces and countries, while the burden of COPD is higher in Québec than in the rest of Canada.

Given the cost information provided by key informers, the marginal annual cost of a portable compressed gas system (provided to patients in addition to a fixed system at home) is estimated to range from $500 for a patient with limited activity to $2,000 for a very active patient. There are about 450 portable systems in use in the Montréal and Laval regions. Only one program has adopted formal criteria for the use of home oxygen equipment. In addition, there are widely differing views on the ideal candidate for home-based portable oxygen therapy.

Access to portable therapy is not uniform throughout Québec, which raises the issue of equity, not only with respect to the existing distribution of services but also with respect to the changes that should be proposed to help policy makers reach informed decisions, once evidence becomes available.

It is unlikely in the near future that conclusive scientific evidence regarding the clinical efficacy and cost effectiveness of portable oxygen therapy will be available to guide Québec policy in this area, although it is hoped that the results of the clinical trial will be a step in this direction. In the meantime, however, in order to build a system based on criteria such as transparency, efficiency (i.e., the rational use of existing resources) and equity, as well as on fair decision-making processes, it is proposed that any policies on the use of portable oxygen therapy in Québec take into account the priorities listed below, that is, it would seem advisable to:

1) Define, by clinical consensus and with the involvement of patients or their representatives, the indications and contra-indications for the use of the different portable oxygen systems as part of long-term oxygen therapy and to determine areas of clinical uncertainty regarding their use;
2) Develop a standardized instrument for the clinical assessment and prescription of portable oxygen equipment and for monitoring eligible patients (this could be a component of a tool developed specifically for home oxygen therapy services);
3) Establish standardized procedures for the prescription and coverage of portable oxygen equipment. Two possible options are **a)** to consider portable oxygen therapy an "exception treatment" (in line with the principle governing exception drugs) or one

intended for patients viewed as "exception patients." This would mean that the RAMQ would make case-by-case decisions about access to portable oxygen therapy in response to physicians' requests and in accordance with pre-determined indications; and/or **b)** to develop routine, systematic procedures for audit review and monitoring of prescription and use in accordance with established indications and procedures for prescribing this therapy. (This option could build on administrative procedures currently in effect in some regions for home oxygen services);

4) Set up a clear and transparent structure for LTOT in Québec with a central body or forum mandated to oversee the development of a coherent home oxygen program across the province. This would include a standardized coverage policy for home oxygen therapy, including portable therapy, which would be homogeneous across the province but which could be adapted to suit the specific characteristics of the region and to meet the particular needs of the local population. Information about available services could be disseminated to patients via patient associations; and

5) Consider establishing a central patient registry for home oxygen therapy that would include information about the prescription and utilization of portable systems and that could be used to monitor access, care delivery and patient outcomes.

The options described above could be the mandate of groups or networks already involved in the treatment or research of COPD (e.g., the Québec Association of Respirologists or the respiratory research network of the FRSQ). These groups would work in partnership with the MSSS and with the involvement of concerned groups of patients and health professionals.

DEFINITIONS

Long-term oxygen therapy (LTOT)

Long-term oxygen therapy refers to the provision of home-based oxygen therapy on a continuous basis (for at least 15 and up to 24 hours a day) and on a long-term basis (for more than three months) to correct chronic hypoxaemia appearing in chronic respiratory diseases.

Long-term oxygen therapy can be provided by a fixed (i.e., stationary) system of oxygen supply (oxygen concentrator or large cylinders of compressed or liquid gas) or by a combination of fixed and portable systems, as briefly described below.

In most countries, LTOT is prescribed by respirologists.[1] The involvement of general practitioners, paediatricians and other specialists varies from one region and country to the next.

Oxygen delivery systems

Most patients on LTOT receive oxygen through a continuous flow nasal cannula. Yet this form of delivery is highly inefficient because only about 17% of the gas participates in the actual gas exchange; the balance is wasted to environmental air [Tiep, 1990]. This inefficiency is only a concern when patients use liquid-oxygen or compressed-oxygen gas tanks. In the 1980s, three types of oxygen-conserving devices were developed: transtracheal catheters, reservoir cannulas and electronic-demand oxygen delivery devices. These systems reduce the amount of wasted oxygen, which helps decrease costs and increase the portability of the device since the oxygen in the reservoir lasts longer.

Portable oxygen therapy

In this report, portable oxygen therapy refers to the use of small oxygen cylinders (compressed gas or liquid) that patients can carry or push themselves (e.g., shoulder bags or small trolleys) during exercise and daily living activities (within or outside the home). Portable systems usually weigh under 4.5 kilograms (10 lbs). Small cylinders of compressed gas provide about two hours of use at 2 L/min oxygen flow rate.

In the United States, the term "ambulatory" often refers to therapy and services that are provided outside a hospital. In the case of oxygen therapy, a distinction is also made between *portable* systems that patients can transport in strollers or on pushcarts, and *ambulatory* oxygen systems that patients can carry or wear. Because the term "ambulatory" is potentially confusing, we have avoided it, except when it is explicitly defined. For the purposes of this report, the term "portable" refers to all non-fixed oxygen-delivery systems used by patients.

Supply systems

There are three stationary sources of oxygen supply available for home use: oxygen concentrators, compressed-gas cylinders and liquid-oxygen reservoirs. Portable oxygen systems are available for use with compressed gas or liquid oxygen. A brief description is provided below [Weg and Haas, 1998; Levasseur et al., 1998]:

1 The meaning of the term "respirologist" used in this report includes all physicians with specialist training in respiratory/chest medicine, e.g., pulmonary or respiratory physicians, chest or lung specialists.

Oxygen concentrators

Concentrators are electrically powered molecular sieve beds that filter and concentrate oxygen molecules from ambient or room air, generating concentrations of 90-98% oxygen. Maximal flow rates are 3-5 L/min. They are the preferred source of home oxygen for patients on long-term continuous oxygen therapy because the supply is constant and total costs for these systems are lower than for those that use gas cylinders. Concentrators weigh between 18 to 27 kg on average and are about the size of a home humidifier. They can be used with several metres of oxygen tubing to provide some mobility within the home, although the concentration and flow diminish if the tube is too long. Concentrators generate some heat and emit a constant low rumbling sound when in operation. Patients usually have a medium-sized backup cylinder that they can use in the event of a power failure. The use of a concentrator slightly raises people's electricity bills.

Oxygen concentrators are currently the predominant form of oxygen supply for LTOT in Québec. Hydro-Québec maintains a list of patients who require a constant source of electricity for medical equipment; however, this information is provided at the patient's discretion.[2]

Compressed-oxygen cylinders

This form of oxygen supply is particularly useful in the absence of a reliable electrical source and for short-term therapy. The large cylinders (H size) weigh around 67.5 kg and can provide oxygen for about 57 hours at 2 L/min; flows can go up to 15 L/min. A mid-sized cylinder that weighs between 6 and 7.5 kg provides oxygen for about 5.5 hours at 2 L/min. This cylinder, however, requires a cart to wheel it around and is appropriate for patients who only occasionally leave their homes. Small lightweight aluminum cylinders of compressed oxygen can be carried in a shoulder bag but last only from between 1 to 3.5 hours at 2 L/min. All compressed-oxygen cylinders must be provided by authorized oxygen suppliers; patients cannot refill portable cylinders on their own because of the safety hazards involved in handling compressed gas.

Liquid-oxygen system

This system comprises a large cylinder of liquid oxygen (oxygen maintained in a liquid state at an extremely low temperature) that functions as a reservoir and fixed system and comes with lightweight portable tanks. The reservoir lasts from about five to seven days at 2 L/min. Valves occasionally freeze at high flows (8 L/min). When this system is not in use, the liquid oxygen gradually evaporates. Equipment and delivery costs are typically from three to four times higher than those of concentrators. Portable cylinders of liquid oxygen weigh from 2.5 to 4.5 kg (lighter than compressed-gas cylinders), and last 8 hours at 2 L/min (about four times as long as portable compressed-gas cylinders). Liquid-oxygen cylinders can deliver high flow rates for longer periods than gas cylinders. Portable tanks can be refilled from stationary reservoirs by patients/carers who have had the proper training.

Given its relatively high cost, liquid oxygen is covered by the public system in Québec only in exceptional cases (e.g., patients who spend considerable amounts of time outside the home for employment or leisure activities, or those requiring high flows). This does not prevent patients from making their own private arrangements with liquid-oxygen suppliers.

2 HMR has developed a standardized form to collect pertinent information to be submitted to Hydro-Québec.

ABBREVIATIONS

AADL	Alberta Aids to Daily Living Program
AETMIS	*Agence d'évaluation des technologies et des modes d'intervention en santé*
ANTADIR	*Association nationale pour le traitement à domicile de l'insuffisance respiratoire*
APPQ	*Association des pneumologues de la province de Québec*
BTS	British Thoracic Society
CIHR	Canadian Institutes of Health Research
CLSC	*Centre local de services communautaires*
COPD	chronic obstructive pulmonary disease
CSST	*Commission de la santé et de la sécurité du travail*
FRSQ	*Fonds de la recherche en santé du Québec*
GOLD	Global Initiative for Chronic Obstructive Lung Disease
HCFA	Health Care Financing Administration
HOP	Home Oxygen Program
INSPQ	*Institut national de santé publique du Québec*
L/min	litres per minute
LTOT	long-term oxygen therapy
MRC	Medical Research Council
MSSS	*Ministère de la Santé et des Services sociaux* (Québec Ministry of Health and Social Services)
NCCHTA	National Co-ordinating Council for Health Technology Assessment (UK)
NICE	National Institute for Clinical Effectiveness
NHS	National Health Service (UK)
NHLBI	National Heart, Lung and Blood Institute (US)
NOTT	Nocturnal Oxygen Therapy Trial
NPHS	National Population Health Survey
OPHQ	*Office des personnes handicapées du Québec*
$PaCO_2$	arterial carbon dioxide tension
PaO_2	arterial oxygen tension
PT	physiotherapist
RAMQ	*Régie de l'assurance maladie du Québec*
RCP	Royal College of Physicians (UK)
RCT	randomized controlled trial
RT	respiratory therapist
RRT	registered respiratory therapist
SAAQ	*Société de l'assurance automobile du Québec*
SaO_2	arterial oxygen saturation
SRSAD	*Service régional de soins à domicile*
WHO	World Health Organization

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1 INTRODUCTION AND OBJECTIVES

1.1 INTRODUCTION

This report has been prepared by the *Agence d'évaluation des technologies et des modes d'intervention en santé* (AETMIS) in response to a request from the *Ministère de la santé et des services sociaux* (MSSS)[3] for a summary of the scientific basis underpinning current policy and practice in the use of portable oxygen therapy for chronic obstructive pulmonary disease (COPD).

This request was prompted by two events. *First*, in the mid 1990s, the responsibility for the reimbursement of medical devices (including home oxygen equipment and supplies) was transferred from the *Office des personnes handicapées du Québec* (OPHQ) to the MSSS. The budget for home oxygen services included standard and portable systems. Details of this transfer are described below.

Second, in September 1999, a group of respirologists wrote to the Deputy Minister[4] requesting that the reimbursement of portable oxygen therapy be delayed for two years, under the new arrangements at the MSSS, given insufficient evidence to support the routine availability of portable oxygen, and to allow time for the first-ever clinical trial of portable oxygen to be conducted at Hôpital Laval, Ste-Foy, Québec, funded by the MRC (described below).

This report aims to summarize the best available evidence to date about the role of portable oxygen therapy in the management of COPD, about current practice in Québec, and provide policy guidance in the short term, with the understanding that any recommendations may require modification to take results from the clinical trial into account when available.

3. Direction Générale des Affaires Médicales et Universitaires MSSS—Luc Deschênes (letter of request on file).
4. At that time, the Deputy Minister was Monique Filion, copy of letter on file.

1.2 OBJECTIVES

The objectives for this report are four-fold:

1) To summarize the published scientific evidence relating to the clinical effectiveness, safety, organization, cost effectiveness and quality of care for portable oxygen therapy as a component of long-term oxygen therapy for COPD with severe hypoxaemia. Furthermore, to provide an overview of the documented psychosocial, legal and ethical issues in the provision of portable oxygen services;

2) To broadly describe practice and current issues in the provision of portable oxygen therapy services in Québec;

3) For comparative purposes, to obtain information about other home oxygen programs in Canada that have adopted models of organization and delivery of services reputed to be highly effective and efficient (Ontario and Alberta); and,

4) To draw conclusions and recommendations from the above for Québec in terms of policy, practice and research.

This report considers the evidence regarding the use of portable oxygen therapy for patients with COPD and severe hypoxaemia who have been prescribed LTOT. We recognize that this excludes the 15-20% of patients who require LTOT but do not have COPD. We also excluded consideration of the use of portable systems for patients travelling, short-burst oxygen therapy, and the role of pulmonary rehabilitation programs (exercise therapy) in COPD. The development of policies and procedures for domiciliary oxygen in Québec would, of course, include consideration of all indications for LTOT; we suggest that this could be considered in the work of an expert committee as per the recommendations for this report.

2 QUÉBEC CONTEXT

Three initiatives pertinent to the Québec context for developing portable oxygen therapy are outlined below:

- the transfer and decentralization of administrative responsibility for oxygen therapy services;
- the policy framework for oxygen therapy in Québec published in 2000; and
- the clinical trial (initiated in 2000) of portable oxygen therapy being conducted at Hôpital Laval, Ste-Foy, Québec.

2.1 THE TRANSFER OF THE OPHQ PROGRAM FOR HOME OXYGEN THERAPY

In 1998, the responsibility for the administration of oxygen therapy services in Québec was transferred from the *Office des personnes handicapées du Québec* (OPHQ) to the 18 *Régies régionales* in Québec, under the MSSS. The following outlines the rationale and sequence of events related to this transfer[5].

The OPHQ was established on June 28, 1978 by the Law for the rights of handicapped persons (*Loi assurant l'exercice des droits des personnes handicapées*; L.R.Q., *c.* E-20.1) as an independent government agency under the Council of Ministers. The mandate was to develop programs that enhanced the well-being and social integration of handicapped persons, by providing services, equipment and/or financial support. From the outset, it was understood that these programs, once developed and implemented, would be transferred to the appropriate existing institutional structures, such as health and social services, education, employment, transport, and social security.

About 13 programs were developed by the OPHQ, most of which were considered as complementary funding programs, i.e. they supplement and fill gaps in services, rather than add directly to existing programs such as provided by the *Société de l'assurance automobile du Québec* (SAAQ), the *Sécurité sociale* or the *Commission de la santé et de la sécurité du travail* (CSST).

One of these programs focussed on the needs of patients with COPD, who were considered handicapped persons, and provided equipment and services to support COPD patients at home (including home oxygen therapy)—irrespective of an individual's income. Patients' needs were required to be assessed by a physician and a respiratory therapist, who then prescribed the equipment deemed necessary, including portable cylinders.

Upon reception of a formal request for home oxygen therapy (accompanied by prescription), the OPHQ delivered an *autorisation d'achat* to the patient that would typically include an annual budget for supplies and disposable material (e.g. mask, filters, tubing). About five distributors of equipment were involved in providing the equipment and supplies to the patients. Suppliers invoiced the OPHQ. The number of refills was not specified or limited. Until 1992, 70% of the costs were paid by OPHQ on reception of the bill while 30% was paid later, contributing to delays in service provision. The *Conseil du trésor* requested that the OPHQ change this policy to ensure services would be provided in due time.

In 1987, the *Conseil du trésor* asked the OPHQ to examine more closely the administrative efficiency of a number of their "health" programs, and transfer them to the MSSS. It took 10 years to negotiate this transfer (implemented in 1998), and oxygen therapy was one of the most controversial—from the perspective of all players involved, for the reasons outlined below.

5 André Bovet, OPHQ—telephone interview, February 14, 2002.

In 1998, after several years of discussion, a committee chaired by the MSSS could not agree on common guidelines for oxygen therapy in Québec. One issue at stake was the assessment of the appropriateness of prescribing portable cylinders to all patients. Some clinical providers viewed this as a "luxury" (except for visiting one's doctor) and inefficient use of resources. Committee members also disagreed about the level of centralization required for managing the new program once transferred. In addition, the members did not agree on the criteria that should prevail during the "transition". For instance, acquired privileges had to be maintained for patients who had been on the OPHQ program before the transfer, creating problems of equity amongst all patients.

Nevertheless, as part of this transfer of responsibility for home oxygen services, the Québec MSSS decided to publicly insure portable oxygen therapy. Budgets for home oxygen therapy were established for each of the 18 regions in 1998, based on an allocation of the OPHQ funds. In turn, each region adopted structures and processes determined by them to be most appropriate for the delivery of home oxygen services to their population.

Although there is no data collected routinely on the number of actual or potential recipients of home oxygen services in Québec, it is acknowledged that there are current inequities from one region to another across Québec in terms of access to, and distribution of, oxygen therapy services[6].

2.2 PROPOSED FRAMEWORK FOR OXYGEN THERAPY FOR QUÉBEC

The *Cadre de référence* [MSSS, 2000a] proposes a framework for the organization of oxygen therapy services for the province, now recognized as the document that should define Québec's oxygen therapy policy. The framework defines guiding principles, admission criteria, and roles and responsibilities of the MSSS and the Regional Health Boards. It specifies that other sources of funding (private insurance, SAAQ, etc.) should be used first before considering the use of local budgets, and that less costly equipment should be provided.

The *Cadre* does not address the use of portable cylinders. It focuses on the clinical criteria for home oxygen therapy defined by an expert clinical committee of the Québec association of respiratory physicians [*Comité d'oxygénothérapie à domicile*, 2000]. In terms of decentralization, there is no mention of a role for CLSCs. It specifies that Regional Health Boards should: develop, implement and monitor oxygen therapy programs; manage a regional pool of equipment (using attribution criteria); and assess oxygen therapy programs. The costs of the different types of equipment were presented in the report and are included in section 6 of this report.

The extent to which programs and services comply with the standards in the *Cadre de référence* is uncertain at present. Furthermore, it is not clear who ultimately is responsible for implementing the proposed structures and processes of care for home oxygen therapy in Québec.

6. Laurence Rivet, MSSS—e-mail communication, October 9, 2001.

2.3 QUÉBEC TRIAL OF PORTABLE OXYGEN THERAPY

There have been no published experimental studies of portable oxygen therapy that have assessed the benefits (in terms of quality of life and compliance) and costs of portable oxygen therapy using standardized assessment tools. The first-ever clinical trial of this nature began in 2000 at Hôpital Laval, Ste-Foy, Québec under the direction of Dr. Yves Lacasse, Respirologist (Principal Investigator), funded by the MRC—now Canadian Institutes for Health Research (CIHR). The trial is entitled "Effects of portable oxygen therapy on quality of life in patients with severe COPD"; it was initially anticipated to be completed over three years. The purpose of this study was to investigate the outcomes associated with the use of home-based oxygen therapy alone (via concentrator) in comparison with the addition of portable oxygen therapy. The objectives and methods of this study are outlined briefly here. The preliminary results, as presented at the 2003 Annual Meeting of the Québec Association of Pneumologists are presented in section 5.2.2.

The underlying hypotheses for this study were stated as follows[7]:

a) in patients with severe COPD, portable oxygen therapy improves health-related quality of life, functional status and exercise capacity, when compared with home oxygen concentrators;

b) portable oxygen therapy improves compliance when used in addition to concentrators; and

c) portable oxygen therapy is as cost-effective in improving quality of life as other interventions that aim to alleviate symptoms.

The study sites are Hôpital Laval, Hôtel-Dieu de Lévis and Hôpital Fleurimont. Hôpital Maisonneuve-Rosemont declined to participate in the study due to a lack of resources to support the trial. The sample size needed for the study was estimated at 54 patients.

The trial is a crossover design; patients with severe COPD enrolled in the study will receive each of three therapies for 3 three-month periods: concentrator only; concentrator plus portable oxygen; and concentrator plus compressed air (this arm will control for placebo effects of the portable system on quality of life outcomes). The primary outcome will be quality of life—measured using standardized instruments; secondary outcomes will be functional status, exercise capacity, compliance and marginal cost of portable oxygen.

As at June 3, 2003, data collection was completed for the first 22 patients in the trial; preliminary results were presented at the November 2003 annual meeting of the APPQ [Lacasse et al., 2003] (see section 5.2.3). Recruitment of eligible patients has proven to more challenging than originally anticipated[8].

7. Copy of protocol on file from Dr. Yves Lacasse

8. Dr. Yves Lacasse—e-mail communication to SL, May 30, 2003

3 METHODS

The following methods were adopted for this review of portable oxygen therapy:

- Review of the published literature
- Analysis of data (via established information systems) on the provision of services in Québec for COPD patients
- Semi-structured interviews with clinical and administrative leaders of home oxygen therapy programs in Québec; collection of supporting documentation
- Analysis of data collected in a separate study of CLSCs in Québec regarding involvement in home care services
- Key informant survey with home oxygen program leaders in other jurisdictions (Ontario and Alberta); collection of supporting documentation

In addition, we followed the progress of the multi-centre clinical trial of portable oxygen therapy based at Hôpital Laval (Québec) under the direction of Dr. Yves Lacasse.

3.1 REVIEW OF THE LITERATURE

The literature search included items indexed up to the end of May 2003.

The following databases were searched:

- PubMed (National Library of Medicine; includes Medline and pre-Medline) (1980-2003)
- HealthSTAR (1980-2003)
- BIOETHICSLINE (1992-2003)
- Current Contents (1999-2003)
- The Cochrane Library (2001, 2002 and 2003—Issues 1 and 2)
- The Québec MSSS Library (1980-2003)
- AETMIS Resource Centre

The search terms included: oxygen, home, domiciliary, portable, ambulatory, oxygen services, COPD, safety, organization, economics, ethics OR ethical, law OR legal. The search was limited to papers published in English and French. Papers published in other languages with English abstracts were not included given the difficulties related to assessing the validity of the research and/or interpreting the results.

For the section on clinical effectiveness, the search was limited to clinical trials of portable oxygen therapy, and data from longitudinal cohort studies. For the sections on cost-effectiveness, safety, organization and ethical-legal issues, a broader range of study methodology was considered, including: prospective controlled studies; retrospective reviews; surveys of utilization; case studies; descriptive studies; comparative studies; costing studies; economic evaluations; and, review papers.

Given that the Québec trial was premised on the lack of scientific evidence investigating the costs and benefits of portable oxygen therapy, relatively broad inclusion criteria were established for research reporting data on the clinical and cost-effectiveness of portable oxygen therapy:

- Sample group included COPD patients with hypoxaemia
- Patients received portable oxygen (via compressed gas or liquid delivery systems) as a component of LTOT therapy at home
- Cohort analysis (retrospective, prospective, or cross-sectional design) or randomized trial evaluation
- Outcomes assessed included quality of life

Abstracts retrieved via electronic searches were reviewed by two researchers (SL and PL) to identify appropriate studies for inclusion in this review. A database of studies collected for the

review was established at AETMIS (by SL) using ProCite Version 5.

For this review, approximately 330 papers were initially retrieved for consideration; additional papers were identified in reference lists of retrieved and other documents; data/information from 139 papers was extracted for this report and included in the reference list. Twelve studies (summarized in Appendix C) were retrieved that contained data relevant to the clinical effectiveness and use of portable therapy; only one [Vergeret et al., 1989] compared portable oxygen therapy versus fixed oxygen therapy using randomized allocation of the patients but non-standardized tools for assessment.

3.2 QUÉBEC DATA ON COPD

Data on hospitalization rates for COPD in Québec, and on estimates of prevalence of COPD were obtained through reports published by MSSS.

3.3 INTERVIEWS WITH KEY PROVIDERS

In Québec, 12 interviews were conducted (7 face-to-face and 5 telephone interviews), involving 22 participants (see table 1 below), with lead clinicians and managers of home oxygen therapy in Québec; site visits were conducted in Montréal, Sherbrooke and Ste-Foy, Québec. Written documentation about programs and services was collected where available during these interviews. One of the three major suppliers of home oxygen equipment and supplies completed and returned the questionnaire regarding suppliers' involvement and perspectives on home oxygen services[9].

The interview framework developed to guide the interviews with the clinical providers is appended (see Appendix A: Interview Framework for Clinical Teams). This was adapted to interview government staff, patient representatives and suppliers (see Appendix B: Survey of Québec Suppliers). Interviews were confidential; participants were assured that comments would not be attributable to interviewees in the final report.

A transcript was prepared from the notes taken during the interviews (SL and PL). Content analysis of the text was conducted as per standard methodology for qualitative inquiry [Patton, 2002; Berg, 2001] to identify descriptive elements and perceptions regarding current issues.

3.4 SURVEY OF QUÉBEC CLSCs

A survey of Québec CLSCs was funded by the Canadian Institutes of Health Research (CIHR, #MA-15472) and conducted in 1999-2001. The aim of the research was to identify the organizational, technical, and human factors influencing the use of technology in home care by all CLSCs in Québec. A mail-back survey was sent to 140 CLSCs. A response rate of close to 70% was obtained for the survey questionnaire which was considered satisfactory given the length of the survey (more than 30 close-ended questions), and given the pressure under which CLSCs were operating—to reorganize and deliver home care services—at the time of the study.

3.5 EXPERIENCE OF OTHER JURISDICTIONS

Lead clinicians and managers were interviewed in Ontario and Alberta (telephone interviews). Method of documentation and analysis was as for Québec interviews.

9. Numerous attempts at follow-up (by telephone and fax) were made to the other two major suppliers in Québec without success.

TABLE 1

Key Informant Survey Participants—Québec

POSITION / PROFESSION	NUMBER
Respirologists	2
Nurses	8
Research physiotherapist	1
Respiratory therapists (RT)	5
MSSS/Régie staff	3
Patient Association rep./carer	2
Supplier	1
Total participants :	22

4 BACKGROUND—COPD

4.1 EPIDEMIOLOGY OF COPD: OVERVIEW

Chronic obstructive pulmonary disease (COPD) is characterized by a substantial reduction in blood-oxygen saturation (chronic hypoxaemia) caused by severe irreversible airway obstruction [Williams and Nicholl, 1985] The predominant symptoms are shortness of breath or breathlessness, cough and sputum production; COPD is characterized by an accelerated decline in lung function and periods of acute exacerbations often requiring hospitalization [Donaldson et al., 2002]. The term COPD includes chronic bronchitis and emphysema (*International Classification of Diseases, ICD9.CM*: 490-492, 496); asthma (*ICD9.CM*: 493) is typically excluded from this disease group. The most important cause of COPD is cigarette smoking; it has been estimated that smoking accounts for 80-90% of the risk of developing COPD [U.S. Surgeon General, 1984; as cited in Brownson et al., 1998].

There is currently no cure for COPD. In addition to oxygen therapy for those with severe COPD with hypoxaemia, disease management strategies include the use of bronchodilators, antibiotics, and pulmonary rehabilitation (exercise therapy). Strategies for primary and/or secondary prevention include smoking cessation and immunization against influenza [Lacasse et al., 1999; GOLD, 2001].

Given the nature of COPD, patients' quality of life may be substantially impaired, as shortness of breath begins to impose restrictions in functional ability, such as reduced exercise capacity and activities of daily living, and contributes to lower measures of well-being, i.e. limited coping skills, impaired cognitive function, high levels of anxiety and depression, and overall poor quality of life [NOTT Group, 1980; Grant et al., 1982; McSweeney et al., 1982; Prigatano et al., 1984; Light et al., 1985; Guyatt et al., 1987; Lahdensuo et al., 1989]. This is consistent with established outcomes for other chronic diseases, although each disease has its own unique profile [Stewart et al., 1989].

COPD is the fourth leading cause of morbidity and mortality in the world [WHO, 2000]; this is consistent with reports for Canada [Lacasse et al., 1999] and the US [Dunne, 2000]. However, it is well established that COPD is under-diagnosed by clinicians and under-recognized by patients. One US study estimated that only between 14-46% of actual cases are diagnosed [Stang et al., 2000]. Furthermore, the difference in prevalence of COPD amongst high and low social groups is perhaps the greatest differential reported for any chronic disease, COPD being high in the lowest socio-economic groups [Prescott and Vestbo, 1999].

Lacasse et al. [1999] reviewed the epidemiological trends for COPD in Canada from 1980-1995:

- COPD was the fourth-ranked cause of death (after coronary heart disease, lung cancer and stroke) and for hospitalization for men over 65 years; for women over 65, it was ranked 7th for mortality and 6th for most frequent cause of hospitalization.
- The total number of deaths from COPD increased from 1980 to 1995 (from 4,438 to 8,583), and continued to increase overall, although deaths in men stabilized; the increase in mortality for women was 241% (1980 to 1995).
- The number of hospitalizations for COPD increased (42,102 to 55,782); average length of stay decreased slightly from 9.6 to 8.3 days over the period 1980-1995.
- The major cause of COPD, and of the increase in mortality, is cigarette smoking.

The most recent estimates of prevalence for COPD in Canada are from the 1998/99 National Population Health Survey (NPHS), as

published in *Respiratory Disease in Canada* [Health Canada, 2001]. In this survey, 3.2% of the adult population over the age of 34 years (2.8% of men and 3.6% of women) stated that they had been given a diagnosis, by a health professional, of either chronic bronchitis or emphysema. The total estimated number of Canadians with COPD in 1998/99 was about 500,000. Prevalence in Canada appears to be consistent with estimates from population studies in the US (5% of the population [National Center for Health Statistics, 1994] and in Europe (4-6% of the population [Gulsvik, 1999]).

Lacasse et al. [1999] concluded that COPD will continue to be a major public health issue in Canada for decades. The authors challenged those who fund and provide health care to find more effective methods of prevention and management of COPD.

4.2 COPD IN QUÉBEC

No routine information is collected or available on the number of people in Québec on LTOT. Information about prevalence and hospitalization rates for COPD in Québec provide some insight into the burden of COPD in Québec, and the potential application of home oxygen therapy.

4.2.1 Prevalence of COPD

The prevalence of COPD in Québec can be estimated from the population health surveys conducted in Québec and for Canada (for comparison). The *Institut de la Statistique du Québec* [2000] estimated overall prevalence for COPD within Québec at approximately 2.5% of the population in 1998. Using total population statistics for Québec[10] in 1999 (the closest year for which population statistics are available; total population 7,349,103), this suggests that the number of cases of COPD in Québec was approximately **183,728** in 1999.

It is likely that the prevalence of COPD is higher in Québec in comparison to other areas of Canada, given higher rates of smoking in Québec, and, related to this, higher mortality rates associated with COPD in Québec as reported below.

4.2.2 Mortality—COPD

Reports published by the MSSS [2000b] and the *Institut national de santé publique du Québec* [INSPQ, 2001] indicate that Québec has the highest mortality rates for chronic respiratory disease (including emphysema, bronchitis and asthma) in Canada. From 1976 to 1997, mortality rates for chronic obstructive lung diseases have increased 52% for men (from 42.0 to 63.8 per 100,000) and 150% for women (from 9.8 to 24.9 per 100,000), mainly due to smoking [MSSS, 2000b]. Overall mortality for men is about three times that for women reflecting heavier smoking among men over many years, although mortality for men has stabilized over the last 10 years, and is still increasing for women. Mortality rates reported for COPD for 1994-1998 were: 63.9 per 100,000 for men; 23.3 per 100,000 for women; 37.5 per 100,000 overall [INSPQ, 2001]. There was a 7% overall increase in mortality for COPD from 1984 to 1998.

Men in Québec and the Netherlands have the highest mortality for COPD in comparison to other industrialized countries [MSSS, 2000b]. The risk of dying from chronic obstructive lung disease for Québec women is three times that of women in Finland, who have the lowest rate.

Although rates of smoking in Québec have decreased overall since 1990, from 39% of the total population to 27% in 1999, this conceals the sharp increase in smoking in youth aged 15-19 (estimated at 36%), where Québec has among the highest rates of smoking in Canada [Health Canada, 2001].

4.2.3 Hospitalization for COPD

Data provided by the Québec MSSS Info-Centre indicates that the number of hospitalizations due to COPD in the province increased over the period 1995-1996 to 2000-2001 (for single and multiple admissions).

10. *Population selon le groupe d'âge et le sexe*, Québec. Available: http://www.stat.gouv.qc.ca, accessed February 21, 2003.

This is consistent with trends for Canada and Québec reported above. It is difficult to know whether the slight increase over time in admissions via the ER is in response to clinical and/or organizational factors (e.g. earlier discharge policies; the *virage ambulatoire*) that would have an impact on the care of COPD patients. Table 2 provides information about the number of single and multiple hospitalizations per year and the rate of hospitalizations where patients were admitted through the emergency room. The proportion of multiple hospitalizations appeared to remain relatively stable over this time period—at about 66% of all hospitalizations. A vast majority of admissions (86-92%) were initiated through the emergency room.

Between 1995 to 2001, for the province of Québec, there were 57,016 patients hospitalized once or more with a primary diagnosis of COPD (36,752 hospitalized once per year; 20,260 hospitalized more than once per year). The majority of hospitalizations for COPD are related to infections.

Data available from 1995/96 through 2000/01, indicate that the mean length of stay per patient with single hospitalization was 12.8 days, while those with multiple hospitalizations was 29 days[11]. The number of days associated with multiple hospitalizations has increased since 1995-1996 while the number of days associated with single hospitalizations has decreased. The proportion of days associated to multiple hospitalizations over the total number of days has increased from 37.5% to 63.2%. This may reflect that efforts to reduce length of stays have been effective for less severely sick patients (single hospitalizations), while length of stays of sicker patients have increased.

4.2.4 Estimate of COPD patients on LTOT

Given the above information, it might be expected that Québec has higher rates of utilization of LTOT for COPD. However, information has not been published regarding the proportion of COPD patients (hospitalized or otherwise) that are typically prescribed LTOT. In Québec, there are no routine information systems, such as the registries for LTOT that exist in other countries (described in sections 6 and 7), that systematically collect or report data on incident or prevalent cases of patients on LTOT. Nor is there information available about the subset of these patients that receive portable oxygen therapy. Given the potential for error in estimating the proportion of patients hospitalized for COPD that might be discharged on LTOT, and the estimated proportion of those that might be prescribed portable oxygen therapy, we felt that, for the purposes of this report, such an estimate would be meaningless. Some (incomplete) data for Québec is reported in section 6 as obtained in the key informant interviews and the survey of CLSCs.

11. Info-Centre, personal communication

TABLE 2

Hospitalizations Due to COPD in Québec (1995-1996 to 2000-2001)

	NUMBER OF HOSPITALIZATIONS			
Year	**Single hospitalization**	**Multiple hospitalizations**	**Multiple/Total hospitalizations (%)**	**Admits via ER*/ Total hospitalizations (%)**
1995-1996	5,775	11,110	65.8	86.2
1996-1997	5,486	11,558	67.8	86.1
1997-1998	6,040	12,599	67.6	89.6
1998-1999	6,592	13,315	66.9	91.4
1999-2000	6,156	12,130	66.3	91.4
2000-2001	6,703	12,049	64.3	92.1

Source: MSSS, Info-Centre, personal communication
*ER: Emergency Room

5 RESULTS OF THE LITERATURE REVIEW

5.1 CLINICAL INDICATIONS

Long-term oxygen therapy (LTOT) is considered standard, evidence-based practice in the optimal management of patients with COPD and severe hypoxaemia given the results of two randomized trials—the British Medical Research Council trial in the UK [MRC Working Party, 1981] and the Nocturnal Oxygen Therapy Trial in the US [NOTT Group, 1980]. These trials established the survival benefits of continuous, low-flow domiciliary oxygen, and have contributed to the high degree of professional consensus around the world regarding the appropriate indications and guidelines for prescribing LTOT.

In their critical appraisal, Lacasse et al. [2001] identified 15 clinical guidelines for COPD in existence internationally. LTOT featured as one of 26 components of the clinical management of COPD specified by the authors; 14 of the 15 guidelines included recommendations for LTOT.

Whether portable oxygen was included within any of these guidelines was not reported.

5.1.1 Clinical profile of patients on LTOT

The following is a brief overview of the typical clinical portrait of patients receiving LTOT at home [Tiep, 1990; Guyatt et al., 2000; NOTT Group, 1980; Crockett et al., 1996; Pepin et al., 1996].

Patients prescribed LTOT are typically over 65 years old, most are men who have smoked for substantial periods of their life, have reduced quality of life given the restrictions imposed by advanced and severe COPD, and have approximately five more years life expectancy. A small minority are able to continue to work, but many are housebound given the severity of disease, physical deconditioning, and/or due to preferences about the use of portable equipment in public. A substantial minority of patients on LTOT continue to smoke while on LTOT. Patients on LTOT may be hospitalized once or more per year due to exacerbations of COPD.

5.1.2 Indications for LTOT

There is good clinical consensus world-wide about the indications for long-term domiciliary oxygen therapy; guidelines are similar world-wide, and are based on the entry criteria for the MRC and NOTT trials [see for example: American Thoracic Society, 1995; Canadian Respiratory Review Panel, 1998; Royal College of Physicians, 1999; Young et al., 1998; Guyatt et al., 2000]. Recently, the WHO and US National Heart, Lung and Blood Institute, via an expert panel of respirologists, published international guidelines for oxygen therapy, under the Global Initiative for Chronic Obstructive Lung Disease [GOLD, 2001]. The GOLD initiative was a response to what was perceived as "inadequate attention from the health care community and government officials" to COPD. In the UK, the National Institute for Clinical Effectiveness (NICE), in association with the British Thoracic Society, is currently developing guidelines for COPD to be published in 2004 [Price and Duerden, 2003]. Only two groups—the US and the UK—have proposed guidance for prescribing portable therapy (see section 5.1.3) within their guidelines for LTOT.

Indications for LTOT commonly include: COPD must be clinically stable, hypoxaemia is verified by an initial blood gas measurement, reduced lung function, as well as additional criteria to accommodate exercise and sleep hypoxaemia [Guyatt et al., 2000]. In their investigation of the appropriateness of home oxygen utilization in Ontario (described in more detail in section 5.3.2), Guyatt et al. are critical of the fact that rigorous follow-up of patients is not commonly featured in the guidelines and procedures followed in many jurisdictions.

In Québec, the recommendations for home oxygen therapy and indications for LTOT have been published by a subgroup of the Québec Association of Respirologists [*Comité d'oxygénothérapie à domicile*, 2000] (table 3). They are consistent with those published elsewhere and are similar to those of the Canadian Respiratory Review Panel [1998] (table 4).

The goal of LTOT is to increase baseline PaO_2 to at least 8.0 kPa (60 mm Hg) at rest, and/or produce SaO_2 at least 90%, which will preserve vital organ functioning with adequate delivery of oxygen [GOLD, 2001].

TABLE 3

Indications for Domiciliary Oxygen Therapy in Québec

Indications reconnues et acceptées	• Les maladies pulmonaires obstructives chroniques (MPOC) en état stable, sous traitement médical optimal, et qui présentent une hypoxémie significative et persistante : une pression partielle de l'oxygène dans le sang artériel (PaO_2) < 55 mg ou une PaO_2 entre 55 et 60 mm Hg associée à une hypertension pulmonaire ou à un cœur pulmonaire. • Les maladies pulmonaires restrictives, sous traitement médical optimal, et qui présentent une hypoxémie significative et persistante. • Les enfants atteints de dysplasie broncho-pulmonaire et qui présentent une hypoxémie persistante (PaO_2 < 60 mm Hg ou une saturation du sang artériel en oxygène (SaO_2) < 92 %.
Indications en voie d'être acceptées	• Les patients cancéreux en phase terminale, qui présentent une hypoxémie persistante et significative (PaO_2 < 60 mm Hg ou SaO_2 < 92 %), et dont la dyspnée ne peut être améliorée avec une médication et une analgésie de confort. • Les patients atteints de MPOC qui présentent une hypoxémie nocturne isolée, avec une SaO_2 < 90 % pendant plus de 30 % de la durée de sommeil, et chez qui un syndrome d'apnée de sommeil a été éliminé par une étude polysomnographique.
Indications controversées et non reconnues actuellement	• L'hypoxémie isolée à l'effort chez le patient atteint d'une MPOC. • L'insuffisance cardiaque chronique. • La présence d'un tabagisme actif chez un patient qui présente par ailleurs les critères d'oxygénothérapie à domicile.

Source: *Comité d'oxygénothérapie à domicile*, 2000 (p. 117).

TABLE 4

Canadian Respiratory Review Panel—Indications

WHEN SHOULD LONG-TERM OXYGEN THERAPY BE CONSIDERED?

PaO_2	SaO_2	Comments
≤ 55 mm Hg	≤ 88%	Patients whose disease is stable on optimal doses of medication should be considered for long-term oxygen.
55-59 mm Hg	89-90%	If patients are exhibiting signs of tissue hypoxia, such as cor pulmonale or erythrocytosis and who desaturate with exercise or only walking.

Source: Canadian Respiratory Review Panel, 1998.

There are differences in the recommended duration of oxygen therapy for LTOT to maximize effectiveness (i.e. from 15 to 24 hours per day). The Canadian Guidelines state that "to be effective, long-term oxygen should be taken for 24 hours per day" [Canadian Respiratory Review Panel, 1998]. This is consistent with US guidelines [American Thoracic Society, 1995]. Québec indications state "l'oxygène doit être utilisé pendant une durée quotidienne minimale de 18 heures" [*Comité d'oxygénothérapie à domicile*, 2000; p. 124]. UK guidelines state that oxygen should be prescribed "at least 15 h per day, although survival improves when used for more than 20 h per day" [RCP, 1999; p. 11]. The Australian and New Zealand guidelines define continuous oxygen therapy as at least 15 hours per day, but note that "as the benefit has been shown to increase with increasing daily use of oxygen for up to 19 hours per day, patients should be advised to use oxygen whenever the physical restriction imposed by the oxygen therapy is not onerous" [Young et al., 1998]. The GOLD [2001] guidelines define LTOT as more than 15 hours per day.

Differing views on the appropriate daily duration of LTOT have implications for the perceived needs and benefits of portable systems for patients who are mobile and participate in activities outside the home.

The goal of LTOT is to increase baseline PaO_2 to at least 8.0 kPa (60 mm Hg) at rest, and/or produce SaO_2 at least 90%, which will preserve vital organ functioning with adequate delivery of oxygen [GOLD, 2001].

5.1.3 Indications for portable oxygen therapy

In contrast to the case for LTOT in general, there is very limited information about referral criteria and utilization of portable systems in the published literature. Two references to portable therapy were located: guidelines proposed by the American Thoracic Society [1995] in the US, and by the Royal College of Physicians [RCP, 1999] in the UK.

In the UK, the RCP published a critical review of domiciliary oxygen therapy in England and Wales that included proposals for prescribing guidelines and assessment tools for portable oxygen therapy [RCP, 1999; summarized by Wedzicha, 1999]. This report was commissioned by the Department of Health.

The RCP indications for prescribing portable oxygen state that the patient must be mobile and needs/able to leave home on a regular basis and that the type of device should depend on patient's mobility. Patients without chronic hypoxaemia must show evidence of exercise oxygen desaturation and improvement in exercise capacity and/or dypsnea with oxygen therapy. In addition to this, patients must demonstrate motivation to use oxygen therapy outside the home (i.e. exercise desaturation alone is not indication for LTOT). Patients must not continue to smoke, as benefits are debatable and risks are considerable.

The report specified that the assessment and prescription of portable oxygen must be undertaken by a hospital specialist. It was

recommended that appropriate portable equipment should be made available on the National Health Service (NHS) drug program. Patients with considerable mobility outside the home require portable liquid oxygen systems or lightweight cylinders with conserving devices; patients with occasional use outside the home require portable cylinders only. The RCP also recommended that an economic evaluation of portable systems be undertaken.

Other significant changes proposed for LTOT included the requirement that oxygen must be prescribed by respiratory physicians or specialists (versus GPs, as was current practice); secondly, that patients require more follow-up than was provided. Consideration of costs and financial implications were specifically excluded from the terms of reference.

In response to the RCP report, the Department of Health initiated a review of the organization and supply of home oxygen services in England and Wales in 2000. A questionnaire (on file) was sent to all public and private providers of services and suppliers of equipments/supplies. It is anticipated that the results of this review will be available later in 2003[12].

In the US, the current guidelines for the diagnosis and care of COPD, published by the American Thoracic Society [1995], include the following statement:

> The standard of care for patients with COPD is for them to be as active and mobile as possible. It is therefore recommended that the oxygen system be stationary with a portable component, unless the patient in incapable or unwilling to be mobile. If the patient is immobile and will not move beyond a radius of 50 ft, an oxygen concentrator with 50 ft of tubing is suitable (p. S92).

This standard is reflected in the following statement from American researchers: "Unless they are immobile or confined to bed, patients should have both stationary and mobile systems of oxygen delivery" [Tarpy and Celli, 1995].

The GOLD guidelines for oxygen therapy do not specify prescribing guidelines for portable oxygen therapy, only that "the prescription should always include the source of supplemental oxygen (gas or liquid), the method of delivery, duration of use, and the flow rate at rest, during exercise, and during sleep" [GOLD, 2001; p. 15].

Donner and Braghiroli [1996] have identified those patients they feel to be best candidates for liquid systems, although they acknowledge that the results of controlled studies should determine the final recommendations for the use of portable oxygen: patients with transtracheal devices who are not confined to bed (these patients require continuous, high flow rates that can be delivered more efficiently via liquid systems); patients involved in exercise rehabilitation programs; and, patients who work or spend a part of each day away from home.

5.2 CLINICAL EFFECTIVENESS

The MRC and NOTT trials investigated the effects of long-term oxygen therapy (delivered predominantly via fixed systems—concentrator, gas or liquid) for COPD patients with hypoxaemia. The protocols included access to portable systems of oxygen supply, although the results did not include an assessment of the use or impact of portable oxygen therapy. A brief overview of the evidence relating to the survival and quality of life benefits of LTOT from these trials and other longitudinal studies is presented below. Evidence regarding the effectiveness of LTOT in COPD is pertinent to portable oxygen therapy given that portable oxygen therapy is a component of, and complementary to, LTOT (i.e. not a substitute therapy); the aim of portable therapy is to improve compliance and quality of life, not survival *per se*. The available evidence specific to portable oxygen therapy is presented in the subsequent section.

12. Jenny Mudge, Department of Health, UK, personal communication, February 4, 2002

5.2.1 LTOT in COPD—Survival and quality of life

5.2.1.1 SURVIVAL BENEFITS

Survival benefits in both the MRC and NOTT trials were proportional to the daily duration of oxygen. In the NOTT trial, mortality was almost double at 2 years for the nocturnal oxygen group (41%; 41/102), who received oxygen on average 12 hours/day, versus the continuous oxygen group (22%; 23/101), who received oxygen on average for 17.7 hours/day. The relative risk of death at 2 years for those in the nocturnal group was 1.94 (CI: 1.17-3.24). In the MRC trial, mortality at 5 years was significantly higher for the control group (66%; 30/45) who received no oxygen therapy, versus the experimental group (45%; 19/42) who received oxygen for at least 15 hours per day. The mean age in both trials was over 65; patients with other major diseases were excluded. These trials demonstrated that some oxygen was better than no oxygen, and that more oxygen (in terms of greater duration) had additional survival benefits—the different interpretations of these results are reflected in the variation amongst the guidelines regarding the optimal duration of oxygen therapy (i.e. from 15 to 18 or 24 hours per day). Given the results of these trials, it is commonly held that LTOT offers COPD patients an additional five years of life [Howard and de Haller, 1991].

A Cochrane systematic review of RCTs of long-term oxygen therapy for COPD [Crockett et al., 2001a] found three further trials [Fletcher et al., 1992; Gorecka et al., 1997; Chaouat et al., 1999]. The Fletcher and Chaouat trials were specific to nocturnal oxygen only, and thus these results are not pertinent to this review. The authors of the systematic review concluded that LTOT improves survival for selected patients with severe hypoxaemia but few co-morbidities; long-term oxygen therapy did not improve survival for patients with moderate hypoxaemia.

Five-year survival rates reported in longitudinal studies of COPD patients on LTOT are highly variable, ranging from 19% [Crockett et al., 2001b], 45% [MRC Working Party, 1981], 40-50% [Hjalmarsen et al., 1999], to 62% [Cooper et al., 1987]. This latter study included only compliant patients. Survival rates reported in other cohort studies have been somewhat lower than the original MRC and NOTT trial results.

Overall median survival in a cohort in Australia [Crockett et al., 1996 and 2001b] was 25 months (21.9 months for males and 29.0 months for females). The authors suggest that the lower survival benefits under clinical (rather than experimental) conditions should be expected, given that the patients were older and had more co-morbidities than those selected for the trials. Reported survival in this Australian study were: 75%, 51%, 19% and 1% at 1, 2, 5, and 10 years respectively. These outcomes were comparable with studies conducted in Sweden [Ström et al., 1991 and 1993] and in Belgium [Dubois et al., 1994].

Pelletier-Fleury et al. [1996 and 1997] reported similar 5-year survival outcomes for patients who received LTOT under either for-profit or not-for-profit organizational arrangements in France (28.2% at 5 years in the non-profit group; 24.74% in the for-profit group).

Predictors of survival for COPD in the study reported by Ström et al. [1991] were: age, sex, smoking status, arterial carbon dioxide tension ($PaCO_2$) when breathing oxygen, and oral steroid medication. This study reported relatively good compliance with treatment (> 15 hours per day) and only 4% whose continuation on LTOT was questionable as per clinical criteria.

Another Swedish study [Hjalmarsen et al., 1999] reported a survival benefit if LTOT was prescribed and care provided by respirologists in specialist units, in comparison to those cared for by internists in general hospitals. This finding is not, however, consistently reported, and has not been the subject of a controlled trial.

Females appear to enjoy significantly greater survival rates on LTOT [MRC Working Party, 1981; Ström et al., 1991 and 1993; Crockett et

al., 2001b]. The reasons for this phenomenon are unclear; compliance for male patients appears to be a contributor to this finding. Survival is also related to the patient's age at initiation of LTOT, whether or not they have just quit smoking, and the number of comorbidities [Crockett et al., 2001b].

A recent review of longitudinal studies indicates a progressive improvement in survival for COPD patients since the 1980s—perhaps due to many factors in the better management of COPD as well as changes in the natural history of the disease [Rennard et al., 2000].

5.2.1.2 QUALITY OF LIFE BENEFITS

Evaluation of the impact of LTOT on quality of life has produced variable results, given that the relationship between hypoxaemia, severity of breathlessness, degree of disability, and impact on quality of life appear to be weak [Stubbing et al., 2002]. Furthermore, the approach to measurement has been variable, in terms of the use of a variety of tools (both disease-specific and not), and in terms of whose perspective is being considered.

Results from the NOTT and MRC trials regarding the impact of LTOT on quality of life are difficult to interpret. The MRC trial [MRC Working Party, 1981] did not use standardized tools to assess quality of life, but reported that improvement in indicators of well-being, improvement in appetite and general alertness were frequently found; many patients showed considerable gains in both social and physical mobility. This group of patients was relatively mobile at baseline. The NOTT trial [NOTT Group, 1980] used three standardized but non-disease specific tools to measure quality of life. At baseline, patients had relatively low levels of self-satisfaction, reduced physical and social capabilities, and increased levels of depression, anxiety and hostility. Most indicators improved significantly after initiating LTOT when all patients were considered (nocturnal and continuous group), although the changes were relatively small—in the order of magnitude of 10%. The authors note that it was possible that improvements were due to the more intensive medical and nursing care received as a study participant.

Some studies have reported improvements in quality of life on LTOT over time [e.g. Ström et al., 1990; Dilworth et al., 1990; Andersson et al., 2002]; other results have been equivocal or unclear [e.g. Lahdensuo et al., 1989; Okubadejo et al., 1996a]. An ancillary study of the NOTT trial, found no improvement over six months in patients with hypoxic COPD treated with oxygen (including portable oxygen) compared to age-matched healthy normal controls without COPD [Heaton et al., 1983]. Finally, some studies indicate that LTOT may have negative consequences for patients' quality of life due to the imposition and restrictions due to the technology itself [Ström et al., 1990] and/or the extended effects of the treatment [Crockett et al., 1996]. Crockett et al. found that the user-friendliness of different types of oxygen delivery systems have different (positive and/or negative) consequences for quality of life on LTOT.

Okubadejo et al. [1996b] were the first to demonstrate a correlation between the severity of illness in COPD (degree of hypoxaemia) and quality of life scores using a disease-specific tool. However, it appears that clinical indications (severity of illness, PaO_2, extent of breathlessness, pulmonary function) may be less related to quality of life for patients with COPD on LTOT, than other factors, such as self-reported tension-anxiety and smoking status [Prigatano et al., 1984], perhaps gender [Crockett et al., 1996], and individual patients' responses to decreased independence in activities of daily living [Okubadejo et al., 1997].

The impact of LTOT on quality of life in patients with COPD and hypoxaemia remains inconclusive to date. This can be explained, in part, by the complex and dynamic relationship between the "forces for decline" and the "forces for improvement" in understanding health-related quality of life (HR-QOL) in chronic disease [Jenkins, 1992]. In the case of COPD, decline is due to the disease process, ageing, and the invasiveness and extended effects of the treatment [Crockett et al., 1996];

improvement could be derived from the extended survival benefits of LTOT therapy, and possible gains in independence in comparison to being restricted to a hospital or in bed at home.

5.2.2 Portable oxygen therapy in COPD

Portable oxygen therapy aims to improve functional capacity and increase duration of therapy [Vergeret et al., 1986]. The rationale for providing portable systems to selected patients is based on: the demonstrated relationship between duration of oxygen therapy and survival benefits; the limitations on patient autonomy imposed by fixed systems; and, the problems of compliance with LTOT outside the context of clinical trials (see section 5.3 on compliance).

Twelve published studies were retrieved for this review that investigated aspects of clinical effectiveness and costs of portable oxygen therapy as a component of LTOT for COPD patients with severe hypoxaemia. These studies are presented below; details are summarized in Appendix C. No published studies were retrieved that investigated the marginal costs and/or cost-effectiveness of portable oxygen therapy in comparison to fixed systems of delivery. The preliminary results of the Québec trial are presented separately below, following the evidence from the published literature.

Only one study was found that investigated the clinical effectiveness of portable oxygen in comparison to fixed systems—a randomized controlled trial conducted in France [Vergeret et al., 1989]. Two randomized trials compared liquid versus compressed gas systems of portable therapy [Andersson et al., 1998; Lock et al., 1992]. The study by Vergeret et al. [1989] also considered the respective advantages of liquid or gas systems. Four studies included some information about the utilization of portable systems [Guyatt et al., 2000; Pépin et al., 1996; Ström et al., 1990; Crockett et al., 1996]. Four studies examined aspects related to the development of prescribing guidelines for portable therapy [Brambilla et al., 1985; Guyatt et al., 2001; Lock et al., 1991; and McKeon et al., 1988]. One final study contributed some information about the costs of oxygen therapy under different administrative structures in France [Pelletier-Fleury et al., 1997].

Vergeret et al. [1989] conducted the largest study (n=159) of portable oxygen therapy to date, investigating the effects of portable systems (compressed gas or liquid oxygen) on duration of therapy and on daily activities in France. No significant clinical or functional differences were found between the group receiving oxygen concentrators only and the group with portable systems. The total duration of oxygen therapy was on average 3 hours longer for those with portable systems, with no difference between gas and liquid systems. For patients using oxygen over 18 hours a day, more patients with portable systems engaged in outdoor walking activities. However, only 60% of those with portable systems used them outdoors and for walking. The research team recommended strict supervision of the use of portable systems in the first three months to best target those patients who will use and benefit from the system.

Vergeret et al. [1989] reported improvements in quality of life for the group that received portable oxygen therapy (versus concentrators only). This conclusion was based on the finding that the group that used more than 18 hours of oxygen per day engaged in significantly more outdoor walking activities; standardized instruments were not used in this study.

In the studies investigating liquid vs. gas systems of portable therapy, both trials reported quality of life benefits for active patients using liquid versus gas portable oxygen systems [Lock et al., 1992; Andersson et al., 1998], although at a cost of almost four times greater. Lock et al. [1992] reported longer duration of use with liquid oxygen; it is difficult to interpret duration from the Andersson et al. study. Vergeret et al. [1989] reported no difference between gas and liquid systems on daily duration.

Utilization of portable systems appears to be less than expected or prescribed. Pépin et al. [1996] reported that only 48% of patients used their portable systems 4 days or more per week; only 4% used their portable system outside the home—almost all of these patients had liquid systems. Vergeret et al. [1989] reported that 40% of patients did not use their portable systems outside the home.

The advantages of standardized exercise testing as part of a formal assessment for portable oxygen therapy have been demonstrated by Guyatt et al. [2001], McKeon et al. [1988] and Lock et al. [1991]. These studies indicate that the benefit of supplemental oxygen could not be predicted by resting pulmonary function tests or arterial blood gases, or by the level of oxygen desaturation on room air during exercise; exercise testing should be a prerequisite for prescribing portable oxygen therapy. Brambilla et al. [1985] demonstrated that desaturation on exercise was corrected by the use of portable oxygen (at 3 L/min), and that the additional weight of the portable system did not impose a significant metabolic burden—i.e. the benefits of oxygen therapy were not negated by the weight of the system. The authors concluded that, for patients that desaturate on exercise, portable oxygen therapy should improve activities of daily living, contributing to enhanced quality of life and physical conditioning of COPD patients.

The Guyatt et al. [2000] review of patients enrolled in the Ontario HOP did not specify what systems patients were using (i.e. what type and combination of fixed and/or portable supply). However, they do note that within this group of patients on home oxygen therapy, about one third were largely restricted to their homes, one third were relatively mobile, and one third spent a large amount of time outside the home—suggesting a large proportion of patients were using portable systems. Overall, 40.5% of patients did not meet the established criteria for LTOT. It was not reported if there were differences in eligibility across levels of mobility. The authors also indicate that almost all patients who did not meet the established criteria for LTOT reported at least moderate subjective benefit from home oxygen, providing support for the possibility of placebo effects of LTOT.

5.2.3 The Québec trial of portable oxygen therapy

The first-ever randomized controlled trial of portable oxygen therapy was conducted in Québec as described in section 2.3. This trial was concluded in the fall of 2003. Preliminary results were presented at the November 2003 annual meeting of the APPQ [Lacasse et al., 2003]. The findings for 22 patients were included in their presentation; final results for 24 patients will be submitted for publication in 2004. The average age of patients was 68 years; 50% were male; 6 continued to smoke. The research team reported no improvement in compliance with portable oxygen and no benefit for patients in terms of quality of life or exercise tolerance, in the three-month period assessed for each of the three arms of the trial: concentrator; concentrator plus oxygen; concentrator plus air. Patients with portable systems used them on average only 0.5 hours per day; there was no difference in utilization when on oxygen or air. The researchers have concluded that there is no justification for prescribing portable oxygen therapy routinely for all oxygen-dependent patients with COPD. Nevertheless, questions remain about the generalizability of these findings given the small sample size and the difficulties encountered with recruitment to this trial (124 eligible patients refused to participate), although the research team is doubtful about the feasibility of conducting any further trials of portable oxygen in the future.

5.3 PROFESSIONAL AND PATIENT COMPLIANCE

Both professional and patient compliance with LTOT is highly variable and, overall, relatively poor. Pépin et al. [1996] identified five factors associated with effective use of oxygen therapy: 1) prescription for 15 hours or more per day; 2) patient education on oxygen therapy by nurse or physiotherapist; 3) cessation of smoking; 4) use of oxygen in all activities of daily living; and, 5) absence of side effects

from oxygen treatment. They concluded that having access to portable systems was an independent factor associated with increased effective use of oxygen therapy, although the authors also concluded that liquid oxygen was associated with better use of oxygen therapy. These authors stress the importance of patient education, and medical and technical follow-up given the finding that patients use LTOT more effectively over time. In their review of the utilization of home oxygen in Ontario, Guyatt et al. [2000] also highlight the importance of rigorous follow-up to ensure appropriate prescription and use of LTOT.

Table 5 summarizes studies that have investigated professional adherence to guidelines and/or patient compliance with therapy.

Both professional compliance, with prescribing guidelines for LTOT, and patient compliance, in adhering to prescribed therapy, are important aspects of understanding the conditions under which the clinical and cost-effectiveness of oxygen therapy (and portable oxygen therapy where appropriate) might be maximized for patients and the health care system. It appears from the literature that there is adequate evidence to support the notion that the management of COPD, and the application of LTOT, is less than optimal in many areas. Rennard et al. [2000, p. 1036] observe that: "Too many physicians and patients are complacent about the diagnosis and management of COPD based on the assumption that relatively little is effective. This prejudice may be complicated by the fact that many patients with COPD suffer from a self-inflicted chronic disease."

The following sections summarize evidence regarding professional and patient compliance with LTOT. There is a limited amount of evidence specific to portable oxygen therapy.

5.3.1 Professional compliance

Studies conducted in different countries have found evidence of inappropriate selection of patients for LTOT as per established guidelines (both under- and over-prescribing).

An estimate of the prevalence of COPD and appropriate utilization of LTOT, as per established guidelines, in Sheffield, UK, demonstrated significantly lower utilization than would be expected [Williams and Nicholl, 1985]. The conclusion to this study was that GPs (who do the majority of prescribing in England) are unable to accurately assess the need for LTOT without specialist advice and clinical measures.

Similarly, Walshaw et al. [1988] found that compliance was better when prescribed by non-respiratory specialists (14.2 hours per day) and respiratory physicians (13.5 hours) than by GPs (10.6 hours), although overall most patients still fell below the UK guidelines of 15 hrs/day.

TABLE 5

Studies of Adherence/Compliance for LTOT

STUDY	PHENOMENON THAT WAS REPORTED	NUMBER OF USERS	COMPLIANCE RATE
Walshaw et al., 1988 UK	Patient compliance	67	55%
Howard et al., 1992 UK	Patient compliance	531	50%
Pépin et al., 1996 France	Patient compliance (+ 15 hours/day)	930	45%
Granados et al., 1997 Spain	Patient and professional compliance	62	31%
Shiner et al., 1997 Israel	Patient compliance (12-24 hours/day)	63	33%
Farrero et al., 1998 Spain	Appropriate use	128	26%

Source: Adapted from Dunne, 2000 (pp. 223-8).

However, in a study conducted in Scotland (where only respiratory specialists prescribe LTOT), found that compliance with guidelines varied considerably and was not better than elsewhere [Morrison et al., 1995]. The average use was 15 hours per day (44% of patients were receiving less than 15 hours of oxygen daily); furthermore, only 14% of patients fulfilled the criteria for prescription of LTOT. The authors reported that the biggest problem appeared to be that most prescriptions were written when the patient was clinically unstable.

Regardless of who prescribes LTOT, it appears that there is considerable room for improvement in terms of prescribing and monitoring patients with COPD (as per established guidelines) to ensure compliance and receive maximal benefits of therapy. Morrison et al. [1995] also noted that LTOT was being prescribed late in the disease, which likely contributed to the higher age of their patients (30% over 70 years) and the number of deaths in the group being studied. These authors argued that the option of alternative modes of delivery in the UK, notably liquid oxygen—as is available in the US and other parts of Europe, although more expensive, might encourage earlier prescription, improved compliance and improved survival.

Despite that LTOT is widely used, and that clinical indications for patient referral are generally agreed, Guyatt et al. [2000] reported a lack of standardization for prescribing and monitoring home oxygen therapy. In their evaluation of 237 patients on LTOT under the Home Oxygen Program in Ontario, Guyatt et al. [2000] found that 40.5% did not meet the HOP criteria for referral to the program. Possible explanations for this finding included: an improvement in patients' clinical condition over time while on oxygen therapy so that they no longer need oxygen, and overly aggressive exercise testing, given the lack of standardized protocols. The first suggestion is consistent with findings from a multi-centre study that found 30% of patients no longer needed oxygen therapy after 3 months of observation [Levi-Valensi et al., 1986]. In the US, Chaney et al. [2002] found that, within 90 days of starting LTOT, 50% of patients no longer met Medicare criteria for therapy; 31.6% of existing patients reviewed no longer met the criteria. Other, smaller studies have also found patients on LTOT with high saturation rates [Pelletier-Fleury et al., 1996], and a tendency for patients to use more oxygen than necessary [McKeon et al., 1987].

Furthermore, Guyatt et al. [2000] found that the prescription of oxygen flow rates varied considerably and were generally higher than

considered appropriate. The authors concluded that the current administration and reimbursement of home oxygen could be more efficient, estimating that a 30% budget reduction (from reducing the number of inappropriate prescriptions of LTOT) would represent $16.5 million in cost-savings for the Ontario health system.

Studies such as the above have emphasized the need for appropriate education of referring physicians, adequate procedures for prescribing and reimbursement, and routine systems of follow-up to decrease the inappropriate use of oxygen therapy. Guyatt et al. [2000] noted that criteria for rigorous follow-up, such as conducted within their study, are uncommon amongst home oxygen programs internationally, and that the cost of a follow-up visit (estimated at less than $7 Canadian) is trivial in comparison to the potential savings to be gained.

The development of standardized assessment and prescription forms specific to portable therapy, such as that proposed in the UK (see Appendix D) and that in use in Switzerland (see Appendix E), are indicative of attempts to establish some accountability through a mechanism that could provide useful data for audit and research.

5.3.2 Patient compliance

Issues pertinent to patient compliance with portable oxygen therapy include: overall compliance with LTOT in general; the actual use of portable systems; continued smoking; and, user-friendliness of the equipment.

Longitudinal and cross-sectional studies in different countries have reported problems of compliance with LTOT, outside the context of a clinical trial [see for example: Vergeret et al., 1986; Okubadejo et al., 1994; Baudouin et al., 1990; Pépin et al., 1996; Ringbaek et al., 2001a]. Most studies report 35-70% of patients using oxygen for 15 or more hours per day. In Denmark, with the lowest reported compliance [Ringbaek et al., 2001b], adherence was particularly poor where non-chest physicians prescribed LTOT. Ström et al. [1991] reported the best compliance, at 70% in a Swedish population, although no explanation was offered regarding their finding. The difficulties involved in measuring compliance were consistently reported in the above studies.

Several studies reported lower usage of portable systems than expected. In the French study by Vergeret et al. [1989], although portable oxygen therapy improved mean daily duration of oxygen therapy, 40% of patients that had portable systems did not use it for activities outside the home. Similarly, Lock et al. [1991] reported that 50% of patients in their UK study used their portable system more than 5 times per week, but only a small number (8 of 50 patients with portable systems) used it more than 5 times a week outside the home. In this study, patients who were formally assessed used their portable oxygen more frequently than those who had not been assessed. Lock et al. recommended that patients receive full explanation of the intent and appropriate use of the equipment and that careful follow-up be instituted.

A later study in France, found that portable systems were only used by 48% of the patients for whom it was prescribed; only 4% (38 patients) used portable systems outside the home—37 of these patients had liquid oxygen systems [Pepin et al., 1996]. The effective use of LTOT was decreased three-fold when a portable system was not available to patients. The authors recommend further investigation into the costs and benefits of the different delivery systems.

Only in Italy is liquid oxygen the preferred source for the majority of LTOT patients, where it reportedly contributes to enhanced compliance [Donner and Braghiroli, 1996]. A pilot study in the UK by Lock et al. [1992] demonstrated that patients increased their activity and use of oxygen when using liquid rather than gas supply of oxygen. In the study by Vergeret et al. [1989] described above, liquid oxygen was preferred by patients for practical reasons, such as weight and ease of refilling, although there was no difference in

duration of therapy between liquid and gas portable systems.

Patient compliance with oxygen therapy was reported to be good in both MRC and NOTT trials, although it was noted in the MRC trial that continuation of smoking was a problem for patients: in the treated group the proportion of smokers decreased from 52% to 44% from start to end of trial; smoking in the control group went from 33% to 27%.

The problem of poor compliance with respect to smoking cessation has been well documented. The proportion of patients smoking while on LTOT ranged from 8-51% in studies reporting this outcome [Pépin et al., 1996; Restrick et al., 1993; Dilworth et al., 1989; Cooper et al., 1987; Morrison et al., 1995; Ström et al., 1991; Prigatano et al., 1984; Walshaw et al., 1988].

Cigarette smoking has been demonstrated to interfere with the clinical effectiveness of LTOT and exacerbate hypoxemia [see, for example: Calverley et al., 1982; Wynder and Hoffmann, 1994]. Continuing to smoke after LTOT has been prescribed also raises issues of safety—in terms of risk of fire (see section 5.4 on safety below), and ethical issues—in term of policies or practice that specifies withdrawal of service if patients continue to smoke (see section 8 on ethical and legal issues below).

Problems related to the user-friendliness of the equipment have been cited as contributing to low levels of patient compliance—with both fixed systems and portable systems of LTOT. For instance, the appearance of the portable systems was problematic for some patients in the Vergeret et al. study [1986]; this research group also reported problems due to the aesthetics of the equipment, the weight, and the limited autonomy of gas systems in their 1989 study. Patients in the study by Lock et al. [1991] reported difficulties with refilling the portable tank and with the limited duration of oxygen supply (mean 78 minutes). Ström et al. [1990] also reported patient difficulties in handling cylinders. Given the restriction in mobility, noise disturbance, and irritation of nose and ears due to the tubing and/or cannula, Restrick et al. [1993] suggest that the provision of LTOT may actually contribute to reduced quality of life to a certain extent. However, active patients using liquid systems reported greater preference for liquid systems given the ease of use and duration of autonomy [Lock et al., 1991; Andersson et al., 1998].

5.4 SAFETY OF OXYGEN THERAPY

Home oxygen equipment is generally considered safe for use by patients given adequate patient education about safe handling, storage and maintenance procedures [Chang et al., 2001]. The key safety concern with home oxygen therapy systems is the risk of fire due to smoking or proximity to open flames and improper handling of the oxygen canisters, given that oxygen markedly enhances combustion [Weg and Haas, 1998].

The following section presents data on: the risk of accidental burns; complications associated with home oxygen therapy; and, technical problems.

5.4.1 Risk of accidental burns

A limited number of reports of burns due to smoking while using nasal cannulas on oxygen therapy at home were identified [West and Primeau, 1983; Minerva, 1991; Petty, 1981; Cooper et al., 1987; Maxwell et al., 1993]. In a review of accidents and home oxygen in the UK, Maxwell et al. [1993] found only seven published reports of accidental burns to patients due to smoking (including studies listed above), although it has been suggested by these authors and others [e.g. Chang et al., 2001] that this type of accident is likely under-reported.

Chang et al. [2001] conducted a retrospective analysis of records in a single burn unit in the US over 12 years and identified 23 patients who had been treated for burns associated with home oxygen use. The average age was 70 years; most had COPD; smoking while us-

ing LTOT was attributed to 70% of the incidents; average burn size covered 4% of their body surface area. It was noted in this study that the type of system in use does not influence the rate of injury as the burns occur at the delivery site (nasal cannula) and not at the source. These authors are concerned that the increasing numbers of patients cared for at home on oxygen will contribute to an increase in number of injuries, and highlight the need for continued emphasis on patient education and monitoring.

Although these findings are not specific to portable oxygen therapy, they underline the need for ongoing patient safety education, the need to monitor patient compliance closely with respect to smoking, and raise concerns regarding the balance of benefits and risks for patients on LTOT who continue to smoke. Given the prevalence of patients who continue to smoke while on home oxygen therapy (see section 5.2 on clinical effectiveness, where studies suggest 25-51% patients on LTOT continue to smoke), it is perhaps surprising that there are not more accidents of this nature.

Chang et al. [2001] cite American Lung Association guidelines for the safe use of oxygen at home: 1) there should be no smoking in the room where oxygen is being used; 2) the oxygen source should be kept at least 10 feet from an open flame, gas and wood stoves, and pilot lights; 3) the oxygen source should be kept at least 10 feet from electrical equipment that may spark.

The Report of the UK Royal College of Physicians [1999, p. 27] lists safety measures to be observed by patients and family members for home oxygen therapy. Beyond the technical maintenance, appropriate storage and careful handling that is relevant to all systems of delivery (concentrator, gas and liquid oxygen) there are safety precautions relevant to portable systems, such as:

- Oxygen cylinders must be stored away from sources of heat and flame.
- Leakage of cylinders must be prevented.
- Liquid oxygen is safer than cylinders given that it is stored at lower pressures, although there is a risk of cold burns; patients and carers must be instructed on the safe handling of cylinders for refilling smaller cylinders.

Given the very low boiling point of liquid oxygen, patients are instructed to wear gloves to protect from burns from the freezing gas when decanting liquid oxygen from the reservoir to the portable tanks [Levasseur et al., 1998].

5.4.2 Complications of therapy

Important clinical complications of oxygen therapy include oxygen toxicity, progressive carbon dioxide retention and local irritation of the nasal area, although they are reportedly rare [American Thoracic Society, 1995; Weg and Haas, 1998]. Ström et al. [1991] reported a small number of patients that developed allergic dermatitis due to the epoxy resin constituents of the nasal cannula; these problems decreased once the cannula was changed for another type without epoxy. Weg and Haas [1998] suggest that topical measures may be effective for the drying, irritation and/or bleeding that can be caused by nasal cannulas, but state that routine humidification is not justifiable with low flow oxygen administration.

No studies were located for this review that commented on clinical complications specific to the use of portable oxygen therapy.

5.4.3 Technical problems

The Swedish Study [Ström et al., 1991] reported the rate of technical breakdowns in oxygen equipment as a component of information collected for the Oxygen Register. On average, 11.6% of concentrators had a defect in a 6-month follow-up period, compared to reported defects for 2.8% of gas cylinders during the same period. The most serious equipment breakdown reported was that six concentrators supplied only room air. These findings are consistent with reports that concentrators are reliable sources of oxygen, but require regular servicing.

No studies were located that reported the nature or frequency of technical problems with portable systems of oxygen therapy.

5.5 TECHNICAL DEVELOPMENTS

5.5.1 Oxygen delivery systems

The traditional delivery system for LTOT has been via a nasal cannula. This system is simple and inexpensive, and is adequate for patients while on concentrators. However, it is inefficient for cylinder and portable systems. New delivery systems aim to reduce the amount of "wasted" oxygen that is lost to the atmosphere with continuous flow systems during the late inspiration and exhalation phases and increase the available oxygen early in the inspiration phase [Tiep and Lewis, 1987]. Three new systems have been developed to conserve oxygen and improve delivery: demand-flow devices, reservoir cannulas, and transtracheal oxygen catheters [Weg and Haas, 1998].

Oxygen conserving devices have been proven to deliver oxygen more efficiently without any decrease in saturation for patients, resulting in longer duration of therapy time available for patients using portable systems [Braun et al., 1992; Tiep et al., 1985; Tiep and Lewis, 1987]. These devices have contributed to decrease costs for portable therapy given: reductions in total oxygen consumption (estimated in the range of 50-75% [Weg and Haas, 1998]); reduction in costs related to refilling and delivering tanks; and, increased potential reduction in overall costs of compressed gas in comparison to liquid oxygen [Tiep et al., 1984]. Tiep et al. [1984] found oxygen saturation levels significantly higher when using the conserving device (due to the bolus of oxygen available from the device), although patient responses regarding the acceptability of the appearance of the device were varied. A pendant style (versus nasal reservoir) increased the patient acceptability of the device [Tiep et al., 1985].

In most health systems, oxygen conserving devices are considered a standard component of the portable oxygen system provided to patients, although not all systems are equally effective during exercise [see for example, Braun et al., 1992; Hagarty et al., 1997]. More research appears to be required to determine the effectiveness of the demand or pulsed system of oxygen delivery, as initial studies have indicated that these systems are less effective at maintaining adequate oxygen saturation during exercise [Senn et al., 1989; Petty et al., 1994]. Transtracheal catheters are inserted directly into the cervical trachea and are suitable for particular patients requiring 24 hour oxygen therapy and those requiring high flows via nasal cannula; however, they are more costly and there is higher risk of local infection and tracheal obstruction by mucous [Weg and Haas, 1998].

5.5.2 Pressuring units—Refillable oxygen cylinders

Cuvelier et al. [2002] have recently demonstrated the potential value of a new device, the oxygen Homefill system (O_2—HF) that permits portable oxygen tanks to be refilled at home from the concentrator. This small RCT (n=10 patients) compared COPD patients' performance on the 6-minute walking tests and found that patients did as well using the refilled cylinders in comparison to standard portable cylinders. As an alternative to traditional portable gas or liquid cylinders, this system may offer reductions in delivery and production costs of portable oxygen therapy and increased convenience to patients.

5.6 ECONOMIC EVALUATION

No economic evaluations investigating the cost-effectiveness of portable oxygen therapy in comparison to fixed systems were located in this review. No published data was found regarding the marginal costs of portable oxygen therapy when added to standard therapy via concentrators or large cylinders of compressed or liquid oxygen. The limited information regarding costs related to portable oxygen therapy is presented below.

From the wider literature on COPD and LTOT, it is clear that COPD represents a significant economic burden on health care systems where it has been assessed in the US, UK, Netherlands and Sweden [Ruchlin and Dasbach, 2001; Wilson et al., 2000; Sullivan et al., 2000; Ward et al., 2000; Guest, 1999; Rutten-van Molken et al., 1999; Jacobson et al., 2000], the main cost drivers being inpatient care, medications and oxygen therapy. Two studies reported a strong relationship between treatment costs and COPD disease severity [Hilleman et al., 2000; Pannier, 1986].

Ward et al. [2000] identified ten components of COPD care, and reported that long-term oxygen therapy constituted approximately one third of the total direct costs of COPD in the US ($US 2.3 billion of 6.6 billion in 1995 values). The costs of LTOT were predominantly related to the fixed costs of the oxygen equipment vs. the amount of oxygen used. In this study, the 1994 Medicare reimbursement rates were $309 per month for stationary administration of oxygen, and $49 per month for the use of short-term portable oxygen, although it is not clear what these rates encompass.

Pelletier-Fleury et al. [1996 and 1997] presented some detailed information pertinent to portable oxygen therapy in a retrospective economic analysis. Clinical and administrative data were available for patients in both systems via the health insurance scheme for self-employed professionals (CANAM). In the 1997 study, Pelletier-Fleury et al. reported that costs related to oxygen therapy represented the largest share of the overall home care costs and were lower for the NP group (72.1% in the NP system; 81.6% in the FP system). One quarter of patients did not meet the agreed clinical criteria for oxygen therapy. A small proportion of patients had portable systems in each group—the difference was not significant; the use of liquid oxygen was very low. Survival was similar in both groups (as reported in section 5.2 on clinical effectiveness).

The total cost of home oxygen therapy (including drugs, physician visits, physiotherapy, oxygen therapy; excluding hospitalization costs) for patients in the non profit (NP) sector was $4,506 per patient per year (reported in 1995 US dollars equivalent; $US1=FF 5.5), versus $5,399 in the for profit (FP) sector [Pelletier-Fleury et al., 1996]. The cost of oxygen therapy was 75% of this figure. The cost varied with the mode of oxygen delivery system and the use of portable systems. Lower costs in the NP sector were associated with the predominant use of concentrators (90% of patients in the NP group; in the FP group, about half used concentrators and half used cylinders), and lower tariffs for portable systems; all other costs were equal. They concluded that as the cost of the delivery system is an important feature of the total cost of LTOT, specific attention should be given to the incentives or motives for choosing different systems and for compliance with national criteria for oxygen therapy.

In France, the remuneration for oxygen therapy services for the NP sector is agreed with the *Sécurité sociale*, prices are set on a district basis and according to mode of oxygen administration [Pelletier-Fleury et al., 1996 and 1997]. The 1994 tariffs set for the NP sector in France were (with or without portable systems): US$7.71 per day for concentrators; US$14.93 per day for compressed gas; and US$18.67 for liquid oxygen. The FP sector prices are set by national regulation, fixed weekly and dependent on the volume of oxygen delivered (more or less than 5 L/min) and whether a portable system is provided. Two fixed rates existed in the FP sector for LTOT prescribed less than 5 L/min (regardless of the

system—concentrator, gas or liquid oxygen): US$10.89 per day without portable oxygen; and US$19.41 per day with a portable system.

In Sweden, Andersson et al. [1998] conducted a cost-utility study in which relatively mobile patients (those who are active outside the home on a weekly basis and able to use portable systems) were randomized to one of two systems: a mobile liquid oxygen system (with portable cylinders) versus a fixed concentrator plus portable gas cylinders. Using standardized but non-disease specific quality of life instruments (the Sickness Impact Profile and the EuroQol), they demonstrated an improved quality of life for those using liquid oxygen, although at direct costs of almost 4 times that of those using concentrators (average total cost of oxygen therapy was US$4,950 for liquid oxygen vs. US$1,310 for 6 months; 1996 values). Clinical outcomes other than quality of life were not measured; no information was reported on utilization rates between the two groups. These authors argue that greater access to liquid oxygen would increase the costs of LTOT, but given the enhancement to patients' quality of life, would lead to higher goal fulfilment in the healthcare sector; "whether this is justifiable or not constitutes a policy issue". (p. 1287)

To summarize, there has been limited economic analysis of portable oxygen therapy, although the above indicates that there are important organizational considerations in the determination of the additional costs of portable therapy, in terms of the structure of administration (NP or FP) and choice of source of portable oxygen (gas or liquid) with potential consequences for quality of life for COPD patients who are active and not housebound.

5.7 ORGANIZATIONAL ISSUES

There is very limited published information about the particular organizational aspects of portable oxygen therapy. However, certain aspects are presumed to follow the pattern reported for LTOT in general.

5.7.1 Access and utilization

The supply and utilization of LTOT varies widely within and between countries [see for example: Williams, 1981; Williams et al., 1983; Garattini et al., 2001], bearing little relationship to the patterns of morbidity or mortality for respiratory disease. This is despite the establishment of almost global consensus on the referral criteria for LTOT. Thus it is presumed that access to portable systems and utilization are also highly variable. Actual rates of utilization have not been published, but this is evident from the general description of services provided in the studies included in the Clinical Effectiveness section. It is likely that these variations are associated with differences in beliefs and practices amongst professionals and patients regarding the value of portable oxygen therapy, rather than due to variations in the pattern of disease and needs.

5.7.2 Source of oxygen

The source of oxygen typically used for LTOT varies greatly between countries. In Europe, the predominant supply is via concentrators (e.g. France, Belgium, Sweden, England, Switzerland and Poland) or gas cylinders (e.g. Denmark, Spain, the Netherlands); the exception to this is Italy, where liquid oxygen is used for 80% of patients [Fauroux et al., 1994]. The authors noted that liquid oxygen has been introduced in Belgium and Sweden for mobile patients (p. 1722).

Liquid portable oxygen therapy is routinely available in the US, as in parts of Europe, for selected patients where it is considered necessary for mobility [Conference Report, 1988]. In the UK, liquid oxygen and most components of portable systems are not available under the National Health Service in the UK, but may be purchased by specialist hospital units or patients themselves [Wedzicha, 1999].

It seems that where liquid oxygen is more widely available, there is a higher utilization of portable systems; substantial variation in access and use of portable systems in Europe has been reported [Vergeret et al., 1989].

5.7.3 Funding arrangements

Most countries have publicly-financed programs for domiciliary oxygen services [see for example: Garattini et al., 2001; Fauroux et al., 1994; Dunne, 2000], with a mixed market of private suppliers of equipment. In Fauroux et al.,'s review of oxygen services in Europe, oxygen equipment is provided by various means and combinations of: commercial companies, hospitals and health services (public and private), and national organizations. Equipment maintenance and technical support is usually provided by commercial companies.

In the UK, the provision of concentrators is funded directly by regional health authorities [Heaney et al., 1999]; installation and maintenance is performed under contract by a supplier. The operating costs of concentrators (e.g. additional electricity costs to the household) may be reclaimed by the user. Back-up cylinders are provided as part of the service contract. If cylinders are prescribed, delivery and maintenance are undertaken by local pharmacies.

In the US, the Health Care Financing Administration (HCFA) funds 80% of Medicare and Medicaid payments to providers of oxygen therapy, and has set guidelines for the prescription of oxygen therapy using the criteria from the NOTT trial [Ward et al., 2000]. The Balanced Budget Act, introduced in 1997 in the US, introduced major funding reductions in home health care [Hafkenschiel, 1997], including the reduction of home oxygen reimbursement rates by 25% in 1998, an additional 5% in 1999, with no rate updates through to 2002.

5.7.4 Follow-up and monitoring

From the literature on LTOT, it is clear that there are substantial efficiencies to be gained through improved arrangements for follow-up and monitoring of COPD patients on LTOT at home [e.g.: Guyatt et al., 2000; McKeon et al., 1987; Ringbaek et al., 2001]. In reviews of home oxygen services in Europe [Fauroux et al., 1994; Garattini et al., 2001], it was noted that home supervision of patients is usually via medical and/or nursing personnel, although the authors note that the quality is highly variable. Using data from the Danish Oxygen Register, Ringbaek et al. [2001b] reported that predictors of "sufficient" follow-up for LTOT patients were: female gender, recent prescription, prescription by a chest physician, prescription for 15 hours or more per day. Where information on portable oxygen systems was available [Lock et al., 1991; Pépin et al., 1996], it was also suggested that regular review of patient compliance and use of portable equipment should be included in routine arrangements for follow-up.

5.7.5 Registers for home oxygen therapy

Four European countries maintain registers for patients receiving home oxygen therapy [Fauroux et al., 1994]: Switzerland (since 1990 via the Association for Tuberculosis and Lung Disease); France (since 1981 via the *Association Nationale pour le Traitement à Domicile de l'Insuffisance Respiratoire Chronique*—ANTADIR); Sweden (the Swedish Oxygen Register started in 1987 by the Swedish Society of Chest Medicine [Ström and Boe, 1988]); and, Poland (since introduction of LTOT in 1986). Registers have recently been established for LTOT in Norway and Denmark; a register for liquid oxygen exists in Norway.

Fauroux et al. [1994] noted that information about LTOT is more difficult to obtain in the Netherlands and the UK; partial information is available from commercial suppliers. They conclude that the most successful data collection is undertaken through national Thoracic Societies, suggesting this approach as a model for other "less well-organized countries, such as the UK and the Netherlands" (p. 1726). Fauroux et al. note that the collection of national information is more complicated in countries where the provision of health care is

organized into different districts or regions, such as in Denmark, Italy, Germany or Ireland.

Where the systematic collection of patient information exists (such as via national/regional registers), it has permitted survival analysis for patients on LTOT [see for example: Ström et al., 1991 and 1993; Chailleux et al., 1996; Healy et al., 1993; Keller et al., 1985; Granados et al., 1992]. In France, ANTADIR manages respiratory care for 32 national regions, covering 70% of all patients receiving respiratory support services. The Swedish Register covers an estimated 90% of all patients in Sweden receiving domiciliary oxygen therapy.

The organization of LTOT in France offers an interesting model of organization. LTOT at home is financed by the national health insurance program (Sécurité Sociale) but provided by private institutions that may be either not-for-profit (NP) or for-profit (FP) organizations. Care for the majority of COPD patients at home is under the auspices of the NP ANTADIR which, as at 1994, provided care for about 17,000 COPD patients in France [Pelletier-Fleury et al., 1997]. ANTADIR provides all technical and medical follow-up for patients on LTOT, negotiates the purchase of oxygen therapy equipment for all NP organizations, and maintains a register of all patients on LTOT. In parallel, for-profit organizations deliver care for about 7,000 COPD patients. Regional centres register detailed data on patient demographics and medical information that is collected centrally. Physicians refer patients to either sector depending on local availability or presence and their preferences for patient care.

5.8 SUMMARY: EVIDENCE ON CLINICAL AND COST-EFFECTIVENESS

The clinical effectiveness of LTOT in COPD with severe hypoxaemia has been demonstrated with distinct survival benefits. There is limited evidence to date to support the use of portable oxygen therapy in selected patients; further investigation into the costs and benefits of portable therapy, such as that currently being conducted at Hôpital Laval, is needed. Problems of compliance persist, highlighting the need for rigorous patient and professional education, and for mechanisms of routine clinical follow-up to ensure sustained benefits and optimal use of the equipment, including assessment of factors related to the user-friendliness of the technology.

6 THE PROVISION OF HOME OXYGEN THERAPY IN QUÉBEC

This section presents the results of the semi-structured interviews conducted with key providers of home oxygen therapy services in Québec, and a summary of the results pertinent to home oxygen services from a survey of Québec CLSCs.

6.1 SUMMARY OF INTERVIEWS WITH KEY PROVIDERS

From the information and data collected during the key informant interviews, the following provides a description of the organizational and financial arrangements for portable oxygen therapy services in Québec, the reported costs of oxygen therapy, and a summary of key issues raised by this investigation.

6.1.1 Organization of home oxygen therapy

There are substantial variations in the way that home oxygen therapy services are organized and financed within and across regions of Québec. In preparation for the OPHQ transfer, each *Régie* was asked by the MSSS to determine the best means of administering the OPHQ programs. Thus, different models of provision for oxygen therapy were adopted in each region. About half of the regions retained a centralized model for home oxygen services managed by the *Régies régionales*, as in Montréal (*Soins respiratoires à domicile* at Hôpital Maisonneuve-Rosemont) and Québec (*Service régional de soins respiratoires spécialisés à domicile* at Hôpital Laval, Ste-Foy). Other regions transferred responsibility (including equipment and budgets for staff) to local hospitals or CLSCs. Given that not all CLSCs have access to respiratory therapists to conduct the assessments and home visits, some CLSCs contract with other CLSCs to provide home oxygen services on their behalf, such as in the Sherbrooke area. Some regions contracted all services for home oxygen therapy to the private sector—a model considered by some of those interviewed to be relatively more costly than via public delivery mechanisms.

It was commonly reported that the distribution of resources, budgets, and management expertise for home oxygen therapy is uneven across the different regions, creating inequities and inefficiencies in access to services. Furthermore, it is very difficult to collect and aggregate data on services across the province. This situation was attributed to the difficulties experienced in the transfer of responsibility from the OPHQ to the MSSS, and in the subsequent decisions taken by individual regions to administer home oxygen therapy. There are waiting lists for portable oxygen equipment in some regions of Québec. Several providers reported that the general shortage of trained respiratory therapists and nurses is another major issue creating problems in the provision of home oxygen services in Québec.

Table 6 summarizes information collected on three major home oxygen programs in Québec: the 2 centralized *Soins à domicile* programs in Montréal and Québec, and the Sherbrooke CLSC home oxygen program. Within each program, the staff (that typically includes a team of respirologists, nurses, RTs, and physiotherapists) conduct patient assessments for home oxygen, arrange for equipment delivery, do routine checks and maintenance, and provide home visits. In the centralized programs, the negotiation with the suppliers and processing of referrals is the responsibility of *régie* personnel.

TABLE 6

Overview of Three Home Oxygen Providers in Québec (2001-2002)

SITE	PROGRAM	PATIENTS	HOME OXYGEN
Hôpital Maisonneuve-Rosemont (HMR) Montréal *Service régional de soins à domicile (SRSAD)*	• Regional program • Process all referrals for home oxygen in Montréal • Initial budget allocation approx $700,000 • Plan to transfer management of program from the *Régie* to HMR in 1-2 years	• 1,818 COPD patients managed by HMR program (1999/00); 50% were new admissions under the regional oxygen therapy program • 58% over 65 • Concern about increasing incidence of COPD and patients eligible for the SRSAD program—estimated increase of 30% per year	• Equipment provided initially for 3-month assessment period; continuation based on outcome of assessment against critera • Approx. 450 patients on portable oxygen systems in Montréal in 2000/01; 2-3 patients on liquid oxygen; no longer a waiting list for equipment • Approx. 1/3 of LTOT patients had portable systems in 2001 (245 of 729) • Equipment distributed in 1999/00*: 156 concentrators; 81 portable systems; 173 regulators; 5 portable cylinders
Hôpital Laval Ste-Foy, Québec *Service régional de soins respiratoires specialisés à domicile*	• Regional program (Québec and east) • Includes respiratory services and ventilator-assisted therapy; program budget: $1.2 M	• 1,300 respiratory patients in program (2001/02); about 70% (900 patients) on LTOT • 73% over 65 years	• About 100 portable systems in stock • Waiting list for portable systems • Only 1-2 liquid gas systems ever used • Informal "ceiling" for home oxygen is approx. $200,000 total expenditure per patient • Requests for support/counselling referred to local CLSC
Sherbrooke CLSC	• CLSC-based home oxygen service; covers 4 CLSC areas (Sherbrooke and 3 other CLSC under contract); copy of contract on file at AETMIS.	• Approx. 150 patients on home oxygen across 4 CLSCs (92 in Sherbrooke CLSC); total number on home oxygen in the Estrie region is 300.	• Separate equipment "pare" for each of 7 CLSCs in the Estrie region • Sherbrooke CLSC has 115 concentrators; no portable systems—all patients pay privately (out-of-pocket or private insurance) for portable oxygen (about $30/month to rent tank; $15 for refills) • All patients with prescriptions for 24/24 hr oxygen (about 50 patients on LTOT) have portable systems (as per CLSC criteria) for back-up • Respiratory therapist uses informal criteria to recommend portable systems to patients with 18-24/24 hr prescriptions; about 50-75 patients in this group use portable systems • Patients pay about $30/month to rent portable systems from suppliers

*Source: *Régie régionale de la santé et des services sociaux de Montréal-centre*, 2000.

The philosophy of patient care also varies amongst home oxygen providers. Some clinical providers clearly focus on their role as specialists versus those that have adopted a more holistic approach. The provision of home care is known to create this kind of tension amongst providers and organizations involved in the delivery of home care—particularly for those working across traditional primary-secondary boundaries [Hollander et al., 2000].

6.1.2 Prescription and financial coverage

The process for arranging home oxygen therapy in Québec follows a relatively standard protocol across different programs. Almost all prescriptions for home oxygen therapy are written by hospital-based respiratory physicians or internists for COPD patients prior to discharge from hospital to home. The prescription usually specifies requirements for fixed and portable systems as per the patients' needs, although walking tests to determine oxygen desaturation and response to oxygen therapy are not undertaken in all centres. All providers referred to the published guidelines in Québec [*Comité d'oxygénothérapie à domicile*, 2000] as the basis for referral decisions for LTOT. More recently, specialists other than respiratory physicians have begun to prescribe home oxygen therapy. GPs do prescribe home oxygen therapy in Québec, although the extent and nature of their involvement is unknown, and likely varies across the province.

The prescription is typically faxed from the hospital to the local home oxygen provider (*Soins à domicile*, hospital or CLSC) who assess the patient's options for financing home oxygen equipment and services. Decisions about financial coverage for home oxygen therapy are usually made within 24 hours to secure arrangements for the delivery of home oxygen equipment and enable the patient's discharge from hospital. The form used by HMR *Soins à domicile* for approval of home oxygen services includes a list of patient indications for portable therapy: physical capacity to leave the home, desire for portable therapy, patient works, participation in social outings and family visits. Furthermore, this program has developed a specific form for portable therapy that details economic, clinical and social criteria for use (see Appendix F).

For each referral, options for private or public (other than Medicare) insurance coverage for home oxygen therapy are sought first to secure payment for the required equipment and services. Québec public insurance schemes include the *Société d'assurance automobile du Québec* (SAAQ), the *Sécurité sociale* (*ministère de l'Emploi et de la Solidarité*), and the *Commission de la santé et de la sécurité au travail* (CSST). Other federal schemes cover native and Inuit populations, the Canadian Armed Forces, and veterans. There are considerable differences in coverage, payment, and organizational arrangements for oxygen therapy under the various public and private programs, contributing to the complexity of this task for the staff making these arrangements. For instance, under the welfare assistance program, home oxygen therapy equipment must be rented from suppliers—an arrangement that is considered by some to be less cost-effective than if these patients were managed under a regional/local program. Private health insurance, through, for example, employee benefit programs, often specifies access to portable systems (in addition to a fixed system). Private schemes are perceived by providers to allow more flexibility, and greater access to portable systems.

Where patients do not have public or private insurance coverage (the majority of cases), then consideration is given to the funds and equipment available (as established by the decentralized budgets from OPHQ) within the home oxygen therapy service (hospital, CLSC, or soins domicile). If no equipment is available, the patient may be asked to pay privately for home oxygen equipment and services, although this occurs by exception according to those interviewed for this report. Arrangements for coverage and access to portable systems appeared to be highly variable (see table 6 above).

The Sherbrooke area home oxygen service has illustrated the decision-making process undertaken by staff to determine the financial arrangements for home oxygen therapy in each patient's case (see Appendix G). It was estimated that this process takes on average (per patient) about 1.5 hours of staff time in communication with suppliers, hospital, home care staff and patients/families.

In Montréal, if a patient of the Chest Institute COPD Clinic is discharged with a prescription for home oxygen therapy, and has private insurance, patients are provided with a list of suppliers and establish their own arrangements for equipment and maintenance. All other patients are referred to the *Soins à domicile* at Hôpital Maisonneuve-Rosemont, who manage the budget for home oxygen services as previously established from the OPHQ. At one time there was a substantial waiting list for both fixed and portable systems in Montréal.

At the time of the transfer of OPHQ to the *Régie régionale de Montréal-centre*, the budget for oxygen therapy was $79,000—an amount that did not accurately reflect the true costs or patient needs in this region[13]. The current budget is approximately $700,000; waiting lists have been eliminated; and the costs of equipment have been substantially reduced through the contractual negotiations with the suppliers. The difficulty in establishing an appropriate budget for the service was one of the main reasons this region opted to maintain central control over the program. The plan is, however, to eventually transfer the management over to the HMR.

6.1.3 Access and supply

Home oxygen therapy in Québec is supplied predominantly by oxygen concentrators. No routine information is collected on the prescription or utilization of portable systems; some ad hoc information was provided for this report. Access to portable systems overall is perceived, by professionals and patients, to be relatively limited in comparison to other provinces and experience elsewhere, although highly variable across Québec. It was reported that in some areas there is no availability of portable systems; in Sherbrooke it appears that up to 75% of patients on LTOT have portable systems, although this is largely via patients paying privately (out-of-pocket or via private insurance). Data provided by HMR (Hôpital Maisonneuve-Rosemont) indicates that approximately 1/3 of their LTOT clientele have portable systems.

Across the province, decisions about the use of portable oxygen are made by different actors in each area—including physicians, respiratory therapists, nurses, patients themselves, and, in some cases, with the involvement of suppliers. Providers appear to have developed their own local norms about the appropriate indications and distribution of portable systems. The stock of portable systems appears to vary considerably between regions.

Professional and patient views on the appropriate prescription and utilization of portable oxygen therapy are also highly variable, ranging from those that believed all patients on home oxygen therapy should have portable systems, to those who felt the current (low) level of access was about right given the severity of illness, age and lifestyles of COPD patients eligible for LTOT. The actual numbers of patients using portable systems is largely unknown given the lack of routine data. Where services have been arranged privately, monitoring of utilization and quality of service is difficult to assess. The use of liquid oxygen in Québec is very rare. Equipment can be rented from suppliers privately (it is not available for purchase), and although actual numbers are unknown, it is believed that private arrangements are extremely rare. It is provided via home oxygen providers for COPD patients who are very active and/or require high rates of flow.

The majority of those interviewed strongly supported the establishment of a centralized storage and maintenance facility for home oxygen equipment (fixed and portable) owned by the CLSCs and hospitals. It was argued that the current mix of arrangements is highly

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inefficient and cumbersome for individual providers to manage. In the decentralization of home oxygen services in the Estrie region to each CLSC, equipment "parks" were also decentralized, creating seven separate facilities (one per CLSC) where there used to be one central park for the region. This has contributed to the complexity of arranging home oxygen therapy—including securing and delivering equipment, discharge planning, and the flow of information between providers, suppliers and patients. In the case of the Sherbrooke CLSC, the home oxygen staff are centralized under contract to Sherbrooke and three other CLSCs, but the equipment is stored and maintained in separate CLSCs. If one of the CLSCs is out of equipment, the patient is asked to pay privately; there is no sharing or borrowing across CLSCs.

There are three major suppliers of oxygen equipment in Québec: Médigas, Vitalaire, and Oxygene 2000. Relationships appear to be positive between the providers and suppliers.

6.1.4 Follow-up

There were differences in local norms for clinical and technical follow-up for patients using home oxygen therapy. In the Montréal region, the equipment is provided by HMR on a three-month assessment basis, enabling staff to monitor patients' adaptation and compliance with therapy. Continuation with LTOT after this period is based on assessment against locally established criteria. This is consistent with the protocol followed in the Québec region. HMR has established guidelines for the withdrawal of oxygen therapy if the patient continues to smoke, although the APPQ recognizes occasions where LTOT may be continued for patients who smoke. Legal advice to the regional program, has indicated that one can't refuse LTOT unless there is a major risk of fire associated with continuation of smoking[14].

In several sites, services related to refilling and delivering oxygen tanks was considered part of package offered or paid for by the insurer, whereas in one case, patients are responsible for travelling to the supplier themselves to arrange refilling or replacing of tanks. The rationale was that if patients are well enough to be ambulatory, they should assume the responsibility (and cost) of this component of their care. Where patients contract privately with an oxygen supplier, only two home visits are included in the agreement per year; additional visits/requests for checks on equipment are at additional cost to patients. Concern was expressed that some patients may be hesitant to request home visits when needed under these arrangements.

6.1.5 Regional and local initiatives

Several mechanisms exist in Québec to support the delivery of high-quality care for COPD patients—including professional/multidisciplinary organizations, research groups and regional/local initiatives. A few of these are listed below:

- There are a number of professional organizations that provide continuing professional education including the ***Association des Pneumologues de la Province de Québec***, the Québec Professional Order of Respiratory Therapists.
- The ***Association pulmonaire du Québec*** (Lung Association) has published a detailed description of services available in Québec for people with respiratory disease [Lanthier and Lanctôt, 1998], guidelines for the establishment of support groups, and a series of seven information booklets for patients with COPD, entitled "Living Well with COPD". One of these is dedicated to long-term home oxygen therapy [Levasseur et al., 1998], with limited information about portable oxygen systems. It states: "You can buy or rent oxygen cylinders from your oxygen company." (p. 15). There is no explanation of financial coverage or organizational arrangements for home oxygen therapy other than: "the cost of using oxygen is different in

14. Personal communication from Dr. Richard Gauthier, October 3, 2003 via external review comments.

each province. Your oxygen supply company, agency or contact person at the health centre can give you more information about the cost of using oxygen." (p. 11.) This booklet includes important safety information for patients.

- **COPD patient support groups** existed at two of the sites visited; at one, the group meet twice a year and focuses on patient education and mutual support (Chest Institute). A third site refers any queries re. support and/or counselling to the CLSC (Laval).

- There have been attempts to develop **standard computerized COPD patient chart** in some areas. In 2001, Dr Raymond Begin, University of Sherbrooke, was nominated for a Chest Foundation Community Service Award for the development of a Web-based medical chart for COPD patients in the Estrie region.

- Local and regional programs to support COPD patients at home have been initiated, such as that in Montréal focussing on self-management [Bourbeau, 2000], and in Sherbrooke focussing on joint hospital-community protocols to manage complications and exacerbations of COPD.

- A new ***Réseau Québecois de l'asthme et de la MPOC*** **(RQAM)** has been established, sponsored by the pharmaceutical industry, whose aim is to "enhance the quality of life of those who are struck by respiratory illnesses and their families" through professional education, diffusion of knowledge, support groups and research on the clinical and organizational aspects of care.

- There is an MPOC research group of 18 researchers led by Dr. Jean Bourbeau at the Montreal Chest Institute within the ***Réseau en Santé Respiratoire du FRSQ.***

- In 1996, a **respiratory day hospital** was established at the Montreal Chest Institute contributing to decreased inpatient stays and reductions in acute emergency visits for patients with asthma, COPD and other respiratory ailments [Schwartzman et al., 2001].

6.1.6 Safety and technical problems

In the qualitative interviews conducted for this review with key contacts in Québec, there were no reported incidents of death or injury in Québec during the last 5 years related to the use of any home oxygen equipment or supplies.

Hôpital Maisonneuve-Rosemont reported a number of minor equipment problems with concentrators and oxygen conserving devices that were repaired under agreement with the supplier.

6.1.7 Cost estimates of portable oxygen therapy in Québec

Obtaining reliable information on costs and prices related to oxygen therapy for this report was very difficult. We used MSSS sources of information, and other cost estimates from individual programs. Table 7 indicates the cost of different pieces of equipment for the provision of oxygen therapy. The total average costs are presented in table 8.

From the above data, table 8 shows the cost of a portable compressed gas system per patient in the first year, if the equipment is purchased (versus rented), using minimum and maximum values, and the equivalent annual cost.

TABLE 7

Home Oxygen Equipment Costs (MSSS)

TYPE OF EQUIPMENT	COST ($)*	DURATION
Oxygen concentrators	1,600-1,800/unit	7 years
Supplies (nasal tubes, filters, etc.)	75-115/year	-
Portable oxygen systems (with oxygen conserving device)	1,000-1,500/unit 10-20/refill	5-15 years (5 years O_2 économiseur)
Supplies for portable systems	60/year	-
Regulators	110-125/unit	15 years

Source: MSSS. *Cadre de référence pour les clientèles nécessitant de l'oxygénothérapie à domicile*. May 2000.
*Estimated 2000 prices.

TABLE 8

Estimates of Cost per Patient for Portable Oxygen Therapy in Québec*

ITEM	MINIMUM COST/ PATIENT	MAXIMUM COST/ PATIENT	AVERAGE COST/ PATIENT	EQUIVALENT ANNUAL COST
Portable equipment with conserving device (compressed gas)	1,000	1,500	1,250	298.72†
Regulator	110	125	117.5	27.14†
Total fixed equipment cost	1,110	1,625	1,367.5	315.86
Refills	120‡	1,440§	780	780
Supplies	60	60	60	60
Total cost	1,290	3,125	2 207,50	1,115.86

*2000 prices
†Average cost discounted at 5%, 5-year life expectancy of fixed equipment, annuity factor = 4.3295 [from Drummond et al., 1997, table 2, p. 94]
‡1 refill/month x $10
§6 refills/month x $20 (use of portable oxygen 1 hour/day at 2 l/min. = 1.5 refills per 7 days = 6 refills per month)

The average cost per patient for a portable oxygen system in Québec is estimated at $1,155.86. The above figure is within the range estimated by *Régie* staff in Montréal for the current cost of the portable system commonly used in this area (a Medigas Pulse-dose system): from $500 (for an elderly inactive patient) to $2,500 (for a young active patient) per year for equipment and supplies for a portable compressed gas system 2000 prices[15]. This does not include the health service costs of the patient assessment in the home by the respiratory therapist, or the routine follow-up visits conducted by a nurse.

6.1.8 Summary of key issues for portable oxygen therapy

The following key issues were raised through the interviews conducted for this review:

- There is a need for standardized indications for prescribing portable oxygen therapy.
- In the absence of convincing evidence, there has been no attempt to develop common referral indications for access to portable oxygen systems; eligibility and allocation decisions are at the discretion of local providers (regional programs and/or

15. Paul Traban—personal communication, May 30, 2003.

individual professionals) and payers (individual patients and/or insurance companies).

- The decentralization of home oxygen services under different organizational arrangements across the province has contributed to wide variations in practice and standards of patient care.
- Inefficiencies in service delivery persist that could be corrected through better management of existing resources.
- There is insufficient information (clinical or administrative) about services, quality of care and patient outcomes for all forms of oxygen therapy to support any evaluative or comparative understanding of the costs and benefits of the current pattern and level of service provision.
- There is limited and variable levels of regional control or monitoring of home oxygen services.

6.2 SURVEY OF QUÉBEC CLSCs

Information about the organization and delivery of home oxygen services was available from the survey conducted by one of the authors (PL) and a research team based at University of Montreal, investigating the involvement of CLSCs in the provision of home care services. The following presents results pertaining to home oxygen therapy services only. For a full description of the study, further analyses and presentation of results, see Lehoux et al., 2001a and 2001b.

6.2.1 Utilization and perceived trends

The survey sought to measure the extent of CLSC involvement in technology-enhanced home care. Ninety-seven CLSCs (of 140 existing in Québec at the time of the survey) responded to this survey, although not all responded to all questions—hence the variation in the denominator in the results reported below.

A vast majority of CLSCs reported involvement in oxygen therapy—the second most frequently reported home care service provided by CLSCs after IV antibiotic therapy. Of them, 83.5% (81/97) were providing fixed oxygen concentrators to clients, whereas 72.9% (70/96) were providing portable cylinders. For fiscal year 1998-99, seventeen CLSCs responded that they provided oxygen services on an ambulatory basis (i.e. via clinics), on average, to 64 patients per CLSC (range: 1-180); 58 CLSCs provided home services, on average, to 53 patients (range: 1-275).

Table 9 indicates the number of CLSCs that reported involvement in the delivery of home oxygen therapy services as a proportion of those that responded to the survey. The total number of CLSCs in each region is indicated (Column A; study period: 1999-2000). Overall, the majority of CLSCs in almost all regions have been involved in the provision of home oxygen therapy services. Not surprisingly, the lowest rates of involvement by CLSCs in the delivery of oxygen therapy services are found in the regions where dedicated oxygen therapy home care programs exist (Montréal and Québec), as well as in a remote region (Abitibi-Témiscamingue).

TABLE 9

Number of CLSCs Providing Home Oxygen Services, by Region

REGION		NUMBER OF RESPONDENTS/ TOTAL NUMBER OF CLSCs	NUMBER OF RESPONDENTS PROVIDING OXYGEN THERAPY-RELATED SERVICES (%)
01	Bas-Saint-Laurent	6/8	6 (100)
02	Saguenay–Lac-Saint-Jean	6/6	6 (100)
03	Québec	5/8	2 (40)
04	Mauricie, Centre-du-Québec	6/10	6 (100)
05	Estrie	5/7	5 (100)
06	Montréal-Centre	22/28	14 (64)
07	Outaouais	5/8	4 (80)
08	Abitibi-Témiscamingue	3/6	1 (33.3)
09	Côte-Nord	3/6	3 (100)
11	Gaspésie–Îles-de-la-Madeleine	5/6	5 (100)
12	Chaudière-Appalaches	8/11	8 (100)
13	Laval	2/4	2 (100)
14	Lanaudière	4/6	4 (100)
15	Laurentides	5/7	5 (100)
16	Montérégie	12/19	12 (100)
	Total	97/140	83 (86)

Table 10 indicates the number of patients on home oxygen therapy for whom individual respondent CLSCs were providing home care services, within each region. This table shows important variations between CLSCs and between regions, reflecting an uneven decentralization of oxygen therapy services across the province. The low number of patients in regions 3 and 6 are understandable given the role played by the major home care programs for COPD patients that are based in Montréal and Québec city. The data for other regions indicate a significant involvement of CLSCs in the provision of oxygen therapy services to COPD patients.

The majority of respondents felt that the number of patients receiving home oxygen therapy had increased for their CLSC from 1996 to the present, while the balance thought the number had remained stable in this time period.

Up to 58% of CLSCs providing oxygen therapy had introduced this service prior to 1990, while 24% did so between 1990 and 1995, and 18% between 1996 and 2000. It seems that most CLSCs were already offering oxygen therapy support prior to the transfer of the OPHQ program in 1998.

Table 11 indicates the modes of access to equipment. It is surprising that up to 44% of respondents indicated "never" loaning equipment from hospital as this is the modality that several Regional Health Boards (including Montréal) has recommended. Almost half of CLSCs (41%) reported "very or extremely often" purchasing concentrators for home oxygen use.

TABLE 10

Number of Patients Receiving Oxygen Services per CLSC, by Region

REGION (number of CLSCs providing data*)		PATIENTS/CLSC											
01	Bas-Saint-Laurent (3)	3	50	35									
02	Saguenay–Lac-Saint-Jean (3)	13	60	75									
03	Québec (-)	-											
04	Mauricie, Centre-du-Québec (4)	20	50	12	80								
05	Estrie (5)	50	28	25	150	80							
06	Montréal-Centre (5)	12	20	8	5	10							
07	Outaouais (4)	250	20	80	20								
08	Abitibi-Témiscamingue (-)	-											
09	Côte-Nord (2)	8	1										
11	Gaspésie–Îles-de-la-Madeleine (5)	76	15	25	50	18							
12	Chaudière-Appalaches (7)	200	56	1	25	50	100	17					
13	Laval (1)	20											
14	Lanaudière (2)	40	35										
15	Laurentides (5)	175	52	35	30	22							
16	Montérégie (12)	60	60	70	30	50	161	5	34	70	45	43	275

*Several CLSCs did not provide figures.

TABLE 11

Modes of Access to Equipment

	NUMBER OF CLSCs	DNA*	NEVER	OCCASIONALLY	OFTEN	VERY/ EXTREMELY OFTEN†
	Respondents	N (%)	N (%)	N (%)	N (%)	N (%)
Rental from hospital	66	24 (36)	37 (56)	2 (3)	2 (3)	1 (2)
Loan from hospital	71	22 (31)	31 (44)	4 (6)	3 (4)	11 (15)
Loan from other CLSC	68	14 (21)	32 (47)	2 (18)	2 (3)	8 (12)
Acquisition from manuf./distributor	71	12 (17)	8 (11)	14 (20)	8 (11)	29 (41)
Rental from manuf./distributor	68	12 (18)	15 (22)	21 (31)	8 (12)	12 (18)

DNA = does not apply (i.e. not perceived as a potential option).
†Values "very often" and "extremely often" were grouped.

The survey revealed that there are important variations in the adoption of user fees across Québec for home-based oxygen therapy (e.g. payment for refilling oxygen cylinders and the delivery of equipment). Fourteen percent of CLSCs mentioned that patients had to pay for acquisition of equipment, 49% for rental of equipment, 18% for delivery of equipment, 63% for refills of oxygen cylinders, 34% for other items. Once a request for home oxygen was made, CLSC staff reported that patients waited up to a maximum of 60 days, with a mean of 4.23 days (standard deviation: 11.39), before receiving the equipment at home.

Eighty-one per cent of CLSCs had adopted a care protocol for home oxygen therapy whereas 5% were using two and 3% were using three different protocols. Up to 39% of CLSCs mentioned that the protocols had been developed in collaboration with a hospital, 26% by a hospital only, and 20% by their CLSC.

6.2.2 Organizational, human and technical factors

The survey explored a number of factors that may help to explain why CLSCs are, or are not, providing technology-enhanced home care. Here, we present their perceptions about the impact of the organizational, human and technical factors on the use of home oxygen therapy (this would include the use of portable cylinders for some patients).

6.2.2.1 Organizational factors

For more than a quarter of CLSCs, the most important barriers to the provision of oxygen therapy were: the "proximity of specialized centres" (25%), the "complexity" of the interventions (26%), the "number of referrals" (29%), and "financial resources" (32%). The factors most frequently perceived as facilitating the involvement of CLSCs in oxygen therapy were "access to equipment" (42%), "development of CLSC expertise in that area" (40%), "CLSC staff attitude" (40%), "CLSC priorities" (32%), and "hospital staff attitude" (32%).

6.2.2.2 Human factors

Respondents felt that some features of oxygen therapy limited its user-friendliness. Up to 35% "disagreed" or "entirely/fairly" disagreed with the statement that with home oxygen therapy "it is easy to resume a normal life"; and 48% with the idea that it "triggers low levels of anxiety." About half of the respondents thought that reliance on a caregiver was necessary. It is perhaps surprising that despite the storage space required by the concentrator, the noise and heat it generates, as well as the impediment of accommodating long tubes for ambulation around the home, 50% of respondents felt the technology fitted into the home environment easily.

Furthermore, the majority of respondents perceived few impediments to the proper use of oxygen therapy by patients. A proportion of respondents reported that the following factors "never" impeded proper use: "lack of financial resources" (24%), "less professional supervision" (21%) and "complexity of the procedure" (19%). Ninety percent of respondents replied that they "agree" and "entirely agree" that they found the technology "simple to use", and 88% replied that they "agree" and "entirely agree" that it "provides autonomy". On the other hand, there was a small proportion that reported the following factors did impede use "very" and "extremely often": "constraints on daily activities" (15%), "less professional supervision" (11%), "lack of support by caregiver" (10%), and "lack of financial resources" (10%).

The fact that there are different responses at either end of the scale is compatible with the diversity in the way that oxygen therapy is distributed and funded across different regions of Québec.

6.2.2.3 Technical factors

There are a number of technical factors or design features that were reported by CLSCs as impeding the use of oxygen therapy. The most frequent are: the "weight of the equipment" (17% indicated "very" and "extremely often"), the "cleaning of equipment" (8%), "access to

components" (7%) and the potential "misfit to home environment" (7%). A number of factors are "occasionally" a concern for a substantial proportion of respondents: the "technical complexity" (55%); the "multiple tasks" (69%); the "design" (60%) and "access to components" (55%).

Regarding the sources of information used by patients and caregivers, a significant proportion of respondents thought that the following sources were used "very" and "extremely often": "patient training provided by the CLSC" (58%), "caregiver training provided by the CLSC" (47%), "written information provided by the CLSC" (40%), and "phone support 24hr/7days—Info-santé" (26%). Interestingly, smaller proportions of respondents thought that patient (30%) and caregiver training (21%) provided by the hospital was used "very" and "extremely often." This seems compatible with the notion that CLSCs and hospitals have not been interacting closely in the provision of high-tech home care.

To summarize, this survey shows that 83.5% of CLSCs are providing oxygen therapy services, although the number of patients served is highly variable (1-275), both within and between regions. Up to 58% of CLSCs provided oxygen therapy services prior to 1990. Most CLSCs buy the concentrators and portable systems. Up to 14% of CLSCs indicate that patients pay for acquisition of equipment. Lack of financial resources and few referrals by hospitals seem the most important organizational barriers to the adoption of oxygen therapy by CLSCs. Respondents felt that it was not easy for patients to resume a normal life with oxygen therapy, and that it significantly raises patients' levels of anxiety. Amongst technical factors, the weight of the equipment and access to components were problematic. Overall, the data suggests that CLSCs are involved to a great extent in the provision of oxygen therapy services, but may not have all the support required to provide those services in a standardized manner across the province.

6.3 SUMMARY—HOME OXYGEN THERAPY IN QUÉBEC

The organization of home oxygen services has assumed widely different models of delivery within each region following the transfer of the home oxygen program from the OPHQ and regional decisions regarding decentralization. Regional services exist in the Montréal and Québec City regions, and, to some extent, the Sherbrooke area. There are relatively few suppliers in the home oxygen market in Québec.

Although the actual distribution and utilization is unknown, access to portable oxygen therapy across Québec was perceived by interviewees as highly variable and relatively restricted overall in comparison to other jurisdictions. There are no commonly accepted guidelines or indications for prescribing portable oxygen therapy. Perceptions about eligibility and the potential benefits of portable therapy are highly variable amongst clinical providers. The extent of patient support and education also appears to be variable between regions.

7 HOME OXYGEN SERVICES IN ONTARIO AND ALBERTA

For comparative purposes, information was sought on home oxygen programs in Ontario and Alberta—two programs reputed to have highly organized delivery of services. For Ontario, this included site visits to the Ontario Home Oxygen Program office and a hospital in Toronto, involving face-to-face interviews with a respiratory physician, a program manager, and an RT. One telephone interview was conducted with a voluntary organization. For Alberta, telephone interviews were conducted with staff responsible for home oxygen services within the Alberta Aids to Daily Living Program, Alberta Health and Wellness. Written documentation was collected on both provincial home oxygen programs.

7.1 THE ONTARIO HOME OXYGEN PROGRAM

The organization of home oxygen services in Ontario is centralized through the Home Oxygen Program (HOP)—a component of the Assistive Devices Program within the Operational Support Branch of the Ministry of Health and Long-Term Care. The HOP provides financial assistance for basic equipment (oxygen delivery system and supplies) to help Ontario residents who have a chronic illness or disability that requires LTOT live independently at home [Ontario Ministry of Health and Long-Term Care, 1996]. Administration of the HOP transferred from the Ontario Drug Benefit Program to the Assistive Devices Program in 1994, as part of an attempt to control the rapidly escalating costs of the program—largely due to the amount of liquid oxygen being used. The costs for the Ontario HOP rose from $18 million (Canadian) in 1985 to $55 million in 1995 [Guyatt et al., 2000].

A HOP document providing information for physicians states:

> If your patient continues to need home oxygen, please help make sure the system used is the one that best meets the person's needs. Almost half of Ontario users are on the most expensive system—liquid oxygen. Other jurisdictions and Ontario hospitals that supply home oxygen have only 10-20 per cent of their users on liquid.[16]

In Ontario, guidelines for eligibility are similar to those in Québec and elsewhere. Prescriptions for LTOT may be written by specialists or GPs. Physicians must complete the medical section of the HOP application form (Appendix H), including the results of an initial arterial blood gas sample and an indication of the degree of ambulation: "Does this person require oxygen outside the home for more than 3 hours/day, at least 3 times/week? If yes, specify …". Patients are directed to contact a registered vendor who specify the oxygen equipment to be supplied, and submit the completed form to the HOP for approval. There are currently over 120 registered vendors of home oxygen equipment and services in Ontario. Either the physician or vendor may specify the type of oxygen delivery system, but it is usually the vendor[17].

Physicians referring patients for long-term oxygen therapy must provide evidence that patients meet certain clinical criteria. Individuals who do not meet the criteria may be referred for individual consideration by a consultant at the Ministry of Health HOP program who can approve patients for LTOT on "compassionate grounds"—a criterion developed in response to physicians' appeals to make exceptions to the agreed standards. A consultant

16. Ministry of Health and Long-Term Care. *Assistive Devices Facts. Home Oxygen Program—Information for Physicians.* Web site document: http://www.gov.on.ca/health/english/pub/adp/oxyphys.html, accessed December 11, 2001.
17. C. Galea, Senior Program Office, HOP program, personal communication, March 4, 2002.

reviews these appeals and makes a decision about whether they should be accepted.

The program pays 100% of the costs of LTOT for patients on social assistance, receiving home care, who are over 65 years old, or who reside in long-term care institutions; the program pays 75% for all others. Patients pay their cost-sharing amount directly to the vendor; the vendor bills the HOP for the balance. The program does not cover patients with equivalent benefits from Workplace Safety and Insurance Board, the Ontario Disability Support Program or the Department of Veterans' Affairs. The costs of disposable supplies are covered by the HOP. Private insurance can be used to cover the cost-sharing amount.

In 1997, a provincial auditor's report criticized the HOP for the prices paid for oxygen services in Ontario (vendors were found to be averaging higher than expected profits); as a result, new prices were negotiated with vendors beginning in 1999; the revised contract was signed in 2001. The fixed rates apply for all vendors across Ontario: $404 per month per patient in the north of Ontario; $383 per month per patient in southern Ontario (rates for 2001/02; $429 in the north and $404 in the south). The fixed price includes all equipment and supplies as required by the patient (except, for example, additional portable cylinders and supplies required for travelling/vacations where patients pay out-of-pocket). The selection of the system (concentrator and/or portable systems; gas or liquid system) is recommended via assessment by the vendor in consultation with the patient and physician. It was noted that most patients receive portable systems in addition to fixed systems; patients that are very mobile receive liquid systems. The rationale for the fixed price was explained as a mechanism to ensure that the incentive for efficiency rests with the supplier to limit unnecessary or inappropriate use of portable systems. The actual use of portable systems in Ontario is unknown; data is not collected routinely on the utilization of portable systems.

In response to a 1999 report on home oxygen funding (OTS/ORCS Task Force, 1999), changes were implemented in 2001 requiring: an initial blood gas result prior to starting LTOT and an oximetry test at 3-months and 15-months after starting on LTOT. It was intended that this would reduce the number of patients who no longer required LTOT[18]. The continuation of oxygen therapy is dependent on documentation of oxygen saturation, although there is no standardization of the assessment or the target level of saturation. The vendors contract with health professionals, registered with the HOP program, to conduct the oximetry testing as required for assessment and monitoring. This arrangement is perceived by the HOP as less than optimal given the potential conflict of interest for the professional.

Interviewees stated that a key challenge in the development of the HOP program is the need to clarify responsibility and leadership for quality assurance throughout the program. The HOP is actively involved in ongoing research initiatives with clinical providers and researchers to investigate aspects of processes and outcomes of home oxygen services.

The review of patients enrolled in the Ontario HOP published by Guyatt et al. [2000] demonstrated that, despite a highly organized model of care and administrative procedures regulating access to LTOT, 40.5% of patients did not meet the established criteria for LTOT. A number of plausible explanations for this discrepancy were offered, including: patients were not clinically stable when assessed, patients' underlying clinical condition had improved, and, the possibility of bias during testing for eligibility due to the assessor and/or equipment errors. The authors emphasized the importance of objective assessments some months following the prescription of LTOT.

18. C. Galea—personal communication, March 4, 2002

7.2 THE ALBERTA AIDS TO DAILY LIVING PROGRAM (AADL)

Home oxygen services in Alberta are, as in the case of Ontario, organized through a centralized government agency—the Alberta Aids to Daily Living Program (AADL)—within Alberta Health and Wellness (Ministry of Health). The AADL Program was implemented in 1980 and covers basic medical equipment and supplies necessary for more independent living at home or home-like setting for people who have a chronic illness or disability. It is based on three principles: equality of access, enhancement of family and community responsibility, and effective resource management [Alberta Health and Wellness, 1999].

The AADL Program is one of two remaining direct service areas for the Ministry of Health (Alberta Health and Wellness); all other direct services were decentralized to the 17 regional health authorities (RHAs) in Alberta under the regionalization program implemented in the 1990's. In 1995, the AADL Program was initially proposed for regionalization; planning was undertaken until 1997, when:

> ... the RHA CEO's expressed concerns with their current ability to implement the program given its various complexities, including the lack of a sound information system accessible by all regions [Alberta Health and Wellness, 1999].

Given these concerns, the government decided to retain central administration of the AADL.

Eligibility criteria for benefits under the AADL are reviewed with the advice of the Respiratory Medical Advisory Committee. Coverage for home oxygen therapy is provided to patients who have documented hypoxaemia. Eligibility criteria are similar to those established in Ontario and elsewhere, except that arterial blood gas results are required prior to starting oxygen therapy, at three months, and at 9-12 months, confirming and re-confirming hypoxaemia at rest on room air. Furthermore, for those patients who desaturate only on exercise, there are criteria for exertional desaturation, to be assessed in a blinded oxygen versus air exercise test, performed at an AADL approved testing centre.

Prescriptions for home oxygen therapy in Alberta must be written by physicians (GP or specialist); the decision about which type of system best meets the patients' clients needs is made by the vendor with the patient during the assessment. Assessment of eligibility and authorization of home oxygen therapy services must be completed by a certified regional respiratory authorizer—a health care professional (e.g. nurse or respiratory therapist) employed by an RHA (i.e. not employed by a vendor) working in hospital or community settings, who has special training in cardiopulmonary assessment, auscultation, modalities of oxygen therapy, interpretation of arterial blood gases and pulse oximetry. Regional training workshops are organized by the RHAs. The authorizer then provides the patient with a list of approved vendors to arrange home oxygen services. The vendor submits all claims (based on set prices) and information (prescription, proof of eligibility, and authorization) to the AADL for approval.

A single payer, flat-rate system for home oxygen services was established in Alberta in 1999 under the AADL. Prior to this, home oxygen services in Alberta were delivered via a mixed system of suppliers (called "respiratory vendors" in Alberta), payers and health service provider arrangements. In 2001/2002, the total AADL budget was approximately $55 million p.a. and provided services to about 69,000 Albertans per year[19]. The total Respiratory Services within this overall budget represents approximately $21 million p.a. of which approximately $20 million is for home oxygen[20].

A single 3-year contract that includes a set schedule of prices (maximum billable amounts) applicable to the 11 home oxygen vendors in Alberta was agreed through a series of discussions and negotiations between

19. AADL website: http://www.health.gov.ab.ca/services/seraadl.htm, accessed January 30, 2002.

20. Telephone interview with C. Brooks, Registered Respiratory Consultant, AADL, March 13, 2002.

the government and the vendor group[21]. In 2002/03 the flat billing fee was $294 per month per patients in urban areas; $321 per month per patient in rural areas[22]. Approximately 80% of patients on home oxygen therapy are in urban centres (most in Edmonton and Calgary); 20% in rural areas.

The above price includes assessment, equipment for one type of system per patient (liquid, gas or concentrator) and basic accessories (including portable systems if appropriate), maintenance, and follow-up by the vendor. Clients pay 25% of the cost of benefits to a maximum of $500 per family per year (this amounts to approximately $75 per month for most clients[23]); clients on income support, those with low income, and those over 65 years old with incomes below the set threshold are exempt from cost-sharing. The vendor is permitted to charge the client for upgrades in equipment, duplicate systems, and other plastic supplies. Plastic supplies cost clients about $10-20/month[24]; some vendors provide these free of charge. The vendor is responsible for invoicing the AADL for benefits provided, and for explaining and collecting the cost-sharing component from the client. An electronic submission and approval process is under development. Patients are generally not eligible for benefits under the AADL if they are eligible to receive comparable benefits under the Workers' Compensation Act, the Department of Veterans Affairs, the Motor Vehicle Accident Claims Act, a private insurance plan, or are Treaty Indians under 65 years (covered by the Medical Services Branch, Health Canada).

21. Sample contract from the AADL (dated July 1999) is on file at AETMIS.
22. Copy of 1999/00 Service Agreement between the Minister of Health and Vendors is on file at AETMIS, current prices obtained via personal communication from C. Brooks, October 14, 2003.
23. As estimated by C. Brooks, AADL Respiratory Consultant—Personal communication.
24. As estimated by C. Brooks.

There are currently no restrictions on portability for patients—vendors must supply whatever volume of oxygen is demanded. The perception at the Ministry is that the majority of patients do not abuse the system, in terms of unnecessary consumption. Vendors have indicated that the usage has increased dramatically since the introduction of the flat rate program. In response, the Ministry initiated an audit of utilization[25] in 2002 to test this claim. The Oxygen Utilization Study was completed in March 2002; the average cylinder usage was 3.2 cylinders per patient per month for the period under review. Usage was considerably less than vendors had perceived[26]. The formal association of vendors is not officially recognized by the government as a negotiating body given concerns about the representativeness of the group.

Given that, in 2002, the Alberta government initiated a review of all health programs in Alberta not insured under the Canada Health Act (including home care programs), interviewees indicated that there was some uncertainty about future developments for AADL programs.

7.3 CONSIDERATIONS FOR QUÉBEC

The following is a summary of the key considerations from the Ontario and Alberta experiences of potential interest to home oxygen services in Québec:

- establishment of agreed principles governing home oxygen therapy service
- formalized criteria for follow-up and monitoring
- efficiency of flat rate mechanism of charging; risk is with vendors to ensure efficiency of delivery
- need to manage carefully the relationship with home oxygen suppliers

25. A 10% random sample of all patients for each vendor was drawn in 2002 to prospectively review utilization for one year.
26. C. Brooks—Personal communication, October 14, 2003.

- need for systematic collection of information about utilization, cost and quality of care to support audit-review-research capacity
- specification of need for portable oxygen therapy in prescription
- centralized administration of home oxygen services—MSSS would need to consider if this would be more or less efficient in comparison with previous OPHQ or current system of administration.

8 LEGAL AND ETHICAL ISSUES

The literature review did not locate any studies that examined the legal or ethical aspects of providing portable oxygen therapy services for COPD. Ethical issues related to the treatment of COPD in general are reviewed in the American Thoracic Society [1995] guidelines, and pertain largely to issues around the use of mechanical ventilation.

Despite the above, several issues of a legal and/or ethical nature were raised during this review, pertinent to the provision of home oxygen services for patients with COPD. These issues are presented below, not for resolution within this review, but with the intent that such issues should contribute to discussions about future policy, practice and research related to LTOT.

Two issues are related to particular legal uncertainties in the provision of home oxygen therapy. The first relates to the legal liability and responsibility of equipment suppliers and manufacturers under variable arrangements across the province (purchase or lease agreements with the *Régies*, home care services, CLSCs or, in some cases, directly with patients). What is their legal responsibility for maintenance, follow-up care, monitoring and safety? Are there particular legal risks associated with the existence of different relationships and arrangements in different jurisdictions? Within individual arrangements, the responsibilities may be clearly articulated, but what would be an optimal and efficient arrangement across all regions for the province?

The second legal issue relates to the seemingly curious situation for securing coverage for home oxygen equipment and services, where alternate sources of coverage (public or private insurance, and, albeit rarely, out-of-pocket payments by patients) are sought in the first instance; coverage under Medicare is accepted as a last option. Under the Canada Health Act, it is not normally possible to provide private insurance for services that are covered under provincial Medicare programs [Romanow, 2002]. The situation for home oxygen services may be particular to the history of provision of services under the OPHQ, but it does appear to be inconsistent with other health care services, given that it is both covered by Medicare and other insurance programs. This possibly reflects the current complex situation for many other home care services, but again, consideration should be given to what might be an optimal and efficient arrangement for providing coverage for this group of patients—most of whom do not have private insurance, but for whom a case-by-case assessment must currently be conducted to establish coverage amongst the many existing options.

Key ethical issues raised by this review are related to the criteria for access to, or distribution of, portable oxygen services and the attitudes associated with the care for people with COPD. The inequities in access to portable therapy across and within different geographic regions is likely indicative of a combination of two factors: the application of different criteria applied (explicitly or implicitly) for patient referral, and the variation in available resources to meet the needs of patients considered eligible for portable therapy. Availability ranges from areas where most patients have portable systems to other areas where portable oxygen is not available at all; waiting lists exist in some areas. One could ask if it is important to distribute equitably a service for which there is little evidence of efficacy. However, there appears to be sufficient evidence and precedent, that there are benefits for some groups of patients and we would argue that, at a minimum, it should be possible to arrive at some clinical consensus regarding a desirable distribution of services for those patients until such time that more definitive evidence is available.

Finally, as noted by Yohannes and Hardy [2003], COPD is generally perceived as a self-inflicted disease that affects the most socio-economically disadvantaged segment of popu-

lations. These authors further note that COPD receives the least amount of research funding in relation to other chronic diseases, and that most COPD research does not target older COPD patients—who merit particular consideration for assessment and disease management. Although rationing health services using age or unhealthy behaviours and/or self-inflicted illness as criteria are usually rejected under explicit processes of decision-making [see for example, Edwards et al., 2003], such criterion may be applied in particular cases at the bedside (see for example, the case of smoking status and access to coronary artery bypass surgery [Langham et al., 1997; Underwood and Bailey, 1993]. It may be useful to consider to what extent such attitudes and practices may be contributing to clinical decisions and policies about the management of COPD and access to portable oxygen therapy in Québec.

9 CONCLUSIONS AND IMPLICATIONS FOR POLICY, PRACTICE AND RESEARCH

9.1 CONCLUSIONS

Patients who require LTOT are typically over 65 years old, smoked for substantial periods of their life, have reduced quality of life given the restrictions imposed by severe COPD, and have approximately five more years life expectancy; a substantial minority of patients on LTOT continue to smoke. Problems of patient compliance with LTOT and portable therapy are well documented, as are discrepancies in professional compliance with established guidelines for LTOT.

The use of oxygen therapy in COPD with moderate to severe hypoxia is well established as an effective technology. There is no evidence to support the use of portable oxygen therapy routinely for all patients on LTOT, yet there is some evidence that some patients with severe hypoxaemia, whose hypoxaemia is reversible with supplemental oxygen on exercise, who engage in activities outside the home, and who are trained and willing to use portable systems appropriately, do enjoy an enhanced quality of life. This is, however, only supported by weak evidence regarding the relationship between portable oxygen therapy and quality of life. Preliminary results from the first-ever RCT of portable oxygen therapy demonstrated no improvement on compliance and no benefit in terms of quality of life or exercise tolerance for the small number of patients included in the study.

Despite the above evidence about effectiveness, it is likely that pressure for access to portable systems will increase, given public and industry demands, and with technological developments to reduce the costs of portable therapy—particularly in the area of short-term oxygen therapy (not the focus of this report). It appears, therefore that systematic mechanisms should be established to set standards for portable therapy for Québec within the broader context of LTOT.

The socio-clinical and organizational challenge appears to be in selecting and monitoring patients to identify perhaps three levels of recipients: 1) those patients most likely to benefit (e.g. patients who are working or participating regularly in activities outside the home); 2) those patients for whom benefits are uncertain; and, 3) those for whom portable oxygen is likely to offer no benefit (e.g. patients who are housebound—either due to their health condition and/or preference). Patients can, of course, move between these levels over time. Public and professional education and monitoring of utilization should be key components of an overall program for LTOT.

Current practice in Québec permits distribution of portable systems in each region, using resources of public programs, without the benefit of an overall framework for service delivery or common criteria for prescribing portable therapy. Overall, access to portable systems in Québec appears to be relatively limited, in comparison to other jurisdictions, although highly variable across different regions. This current pattern of service delivery—including available equipment, human resources, and financing arrangements—contributes to a situation that is neither equitable nor efficient in terms of access and management. The lower level of provision is in contrast to the finding that there is a higher burden of COPD in Québec.

It is notable that, despite common indications for referral in both provinces, the profile of patients on home oxygen support in Québec appears to be different than that in Ontario. Patients on LTOT in Québec were reportedly less mobile than those described in the review undertaken by Guyatt et al. [2000] in Ontario where one third of the patient group were considered very active. It is important to note that 40.5% of the patients in the Ontario study did not meet HOP criteria for LTOT.

In light of the above, one has to remember that restricting access to this technology has direct implications for the mobility of patients, who otherwise must remain in their homes up to 18 hours per day—in compliance with prescribed therapy. From a policy perspective, although the evidence of efficacy may be weak, adopting a position that refuses any access to a relatively safe and inexpensive technology seems unjustified, given that a number of patients are likely to benefit from increased mobility [Johri and Lehoux, 2003].

The recommendations proposed for policy, practice, and research in Québec are outlined below.

9.2 POLICY RECOMMENDATIONS

In all matters, policy recommendations should be grounded in criteria that include the best available scientific evidence, transparency, efficiency (in terms of the rational use of existing resources), equity of access, and fair process of decision-making. It is clear that despite the limited scientific evidence regarding the appropriate use of portable oxygen therapy, much can be done to improve the efficiency and equity of access for LTOT services in general across Québec. Underpinning the following policy recommendations is the evidence that improvements in organizational structure and delivery of care contribute to the overall quality of care, particularly in the area of chronic disease management [Berwick, 2002]. The first consideration in the following policy recommendations is the need to establish clear and consistent policy for portable oxygen therapy, although most also have implications for policy related to all home oxygen therapy services.

Together with this report, the results of the clinical trial of portable oxygen therapy being conducted at Hôpital Laval (when available) could provide an important stimulus for the development of **clinical consensus about the indications** for prescribing portable oxygen therapy, to clearly identify which patients may benefit from access to portable systems. A multidisciplinary working group (including clinical, patient, MSSS, and COPD research network representation), amongst those already in existence, could be appointed with the appropriate support to identify consensus criteria for referral for portable therapy: where clearly indicated, where contraindicated, and, areas of clinical uncertainty in terms of potential benefit.

To support the above work, a **common tool for assessment and prescribing**, such as the forms proposed by the British Thoracic Society (BTS) in the UK and those in use in Switzerland, Alberta and Ontario, could be developed for use in Québec to standardize referral and monitoring arrangements for home oxygen therapy. This would include a reassessment of utilization and need for portable oxygen therapy at three months post-prescription.

The approaches to home oxygen therapy adopted in the US and proposed in the UK are based on the premise that access to such technology contributes to enhancing survival and quality of life for people with severe COPD by promoting independence. Guidelines in these jurisdictions indicate that, unless housebound, and where indicated, portable oxygen therapy is an accepted component of LTOT. The UK domiciliary record form for portable oxygen therapy assessment and prescription includes a section for the documentation of a patients' indications for portable therapy and what type of system is prescribed. This form, however, has yet to be piloted and it is unclear how it will be used—i.e. the procedures for collecting and analyzing the forms to monitor prescriptions.

In Québec, it appears that there are two options regarding the possible direction for **standardized procedures** related to prescribing and approving portable oxygen therapy.

a) to treat the prescription of portable oxygen therapy as a *traitement d'exception* (similar to a *médicament d'exception*) or *patient d'exception*,[27] in which case decisions

27. This is a relatively new program instituted by the MSSS to cover the costs of medications and devices that are not listed in the formulary, but available in Canada, for individual patients who are considered "exceptional".

about access are made on a case-by-case basis, as per agreed indications, by the RAMQ in response to requests from physicians; AND/OR,

b) to establish routine, systematic procedures for audit review and monitoring of prescriptions and utilization against the agreed indications and procedures established for prescribing (this option could build on administrative procedures currently established in some regions for home oxygen services).

The merits of each of the above options should be debated by the MSSS in discussion with respiratory physicians and patient associations in terms of the anticipated costs, benefits, and impact on administrative and professional practice.

The investigation into the current status of portable oxygen therapy services in Québec, though limited, highlighted the need for a **common framework for home oxygen services**, including portable therapy, to establish consistent and standardized policies for access, delivery and coverage across the province. The MSSS and/or the *Régies* could strengthen its leadership/supportive role in creating a central body or forum to oversee the development of standards, co-ordination and quality of care as part of the broader framework for LTOT services in the province within which to develop existing local/regional services. An ideal system may be one that blends regional assessment and supply centres balanced by a central co-ordinating body with access to provincial data.

In Québec, the current reliance on decision-making across a number of different organizational arrangements, most of whom have very limited resources, in an absence of standards for portable oxygen, contributes to what could be described as support for "micro-rationing" and the inconsistent application of criteria for portable services in Québec. Existing resources, where available, are distributed in different ways in different areas of the province, resulting in the current inequity in distribution of services. The problem, however, is not in the number or diversity of models of organization, but in the need to establish common parameters to develop these models in the provision of oxygen services.

Again, a multidisciplinary forum could take a leadership role in designing a comprehensive framework for home oxygen therapy. A further role for this group could be to consider issues in the organizational and financial arrangements for the service delivery component of LTOT. Two issues for specific consideration are: 1) the advantages and feasibility of negotiating a single flat rate for Québec (differentiated for rural and urban areas—as per in Ontario and Alberta; all inclusive price per month for home oxygen); 2) clarifying the respective roles of the health service and the suppliers in the management of equipment; this could include undertaking a cost-minimization study to highlight the potential savings of alternative options. Mechanisms to simplify public coverage for LTOT would contribute to improvements in equity for patients amongst the different public payers, and increase efficiency of decision-making. Information for patients about the availability of services could be designed by this group with involvement from patients, and disseminated via patient associations and providers.

Such a forum as above could also consider principles governing access to portable oxygen therapy, the mechanisms for developing regional/local guidelines for access to portable therapy, and efficient deployment of existing resources—such as the development of centralized pools of oxygen therapy equipment. In the UK, Price and Duerden [2003] bemoan the lack of a national service framework for COPD as an important public health problem, in comparison to that established for coronary heart disease—where there have since been notable improvements in emphasis, coordination and resources. It would seem that the same argument might apply in Québec where consideration might be given to the relative priority afforded to COPD, in terms of the adequacy of the infrastructure to improve the standard and consistency of patient care across the province.

Finally, given the experience of other jurisdictions with home oxygen patient registries, such as in France, there should be some consideration of the costs and benefits of establishing a **central registry** for home oxygen in Québec. Patient registries, or other mechanisms for the routine collection of clinical and administrative data, are considered important elements of organized attempts to improve quality of care, particularly in the area of chronic disease management [Casalino et al., 2003; Griffin and Kinmouth, 2000]. As demonstrated for home oxygen therapy in general, such registries can contribute to the evidence-base for decision-making regarding the processes and outcomes of care, and contribute to audit and research activities. The routine collection of information about home oxygen therapy could help monitor those patients who need, and those who do not need, portable oxygen therapy.

The above recommendations would build upon and strengthen the many local and regional initiatives in Québec to develop home oxygen services identified in this study (see Section 6.1, Summary of Interviews).

To summarize, the recommended priorities for policy development related to portable oxygen therapy in Québec, are:

1) to define, by clinical consensus, the indications, contra-indications, and areas of clinical uncertainty for prescribing portable oxygen therapy within LTOT;

2) to develop a standardized instrument for clinical assessment, prescription and monitoring of patients eligible for portable therapy (this could be a component of an assessment tool developed for home oxygen therapy services);

3) to establish standardized procedures for the prescription and approval of portable oxygen therapy. Two options specific to portable therapy are presented for consideration: **a)** to treat the prescription of portable oxygen therapy as a *traitement d'exception* or *patient d'exception*, where decisions about access would be made by the RAMQ in response to requests from physicians on a case-by-case basis as per agreed indications, AND/OR, **b)** to establish routine, systematic procedures for audit review and monitoring of prescriptions and utilization against the agreed indications and procedures established for prescribing (this option could build on administrative procedures currently established in some regions for home oxygen services);

4) to establish a clear and transparent structure for LTOT in Québec with a central body or forum to oversee the development of a coherent program for domiciliary oxygen across the province. This would include a standardized coverage policy for home oxygen therapy, including portable therapy, that is homogeneous across the province, but with the capacity to adapt models of implementation to regional specificities and local population needs. Information about available services could be disseminated to patients via patient associations; and

5) to consider establishing a central patient registry for home oxygen therapy that will include information about the prescription and utilization of portable systems, and be used to monitor access, processes of care, and patient outcomes.

9.3 IMPLICATIONS FOR PRACTICE

This report has highlighted a number of areas where improvements could be made within current professional practices related to the delivery of home oxygen therapy services, including: patient education and support; professional education about appropriate prescribing practices and follow-up; standardization of practice through the collection and sharing of information about current practices at local, regional and province-wide levels; implementing appropriate follow-up and monitoring arrangements for LTOT; adopting effective strategies for reducing smoking rates—particularly in young women. A number of initiatives to further develop clinical practice for COPD were listed in section 6.1.1. Our approach is to suggest that we build on

these strengths and existing professional networks to push forward on the above items.

9.4 AREAS FOR FURTHER INVESTIGATION

The following list identifies key areas related to this review that require additional scientific investigation (research and audit activities) to inform decision-making at all levels of the Québec health care system (individual, organizational, and policy) regarding the effective application of portable oxygen therapy.

Effectiveness of prevention and cessation of smoking

Innovative thinking and research is required to better address the underlying problem of smoking and its implications for COPD, and ultimately the need for LTOT, given the scale of the problem and the challenges inherent in sustaining efforts to prevent an increase in smoking rates amongst particular groups.

Effectiveness and cost-effectiveness of portable oxygen therapy

Despite the high level of rigour and scientific credibility of the Québec trial, there may be questions about the generalizability of the findings given the size and nature of the sample size. Furthermore, it is generally accepted that substantial changes in practice and policy are unlikely and uncommon on the basis of a single study [O'Connell et al., 2001]. However, given the difficulties encountered in conducting the Québec trial of portable oxygen therapy, it is unlikely that further trials to assess clinical and cost-effectiveness will be undertaken in the future[28]. This points to the need for a more consensual mechanism for determining standards of care and practice for portable therapy.

Delivery systems: Cost-effectiveness and user-friendliness

Further evaluation is needed, in the form of prospective controlled trials, to assess the costs and benefits (including user-friendliness) of different portable delivery systems—particularly liquid and compressed gas supply, and the conditions under which liquid oxygen may be considered appropriate.

Pulmonary rehabilitation programs for COPD

Related to the question of cost-effectiveness of portable oxygen therapy, are outstanding research questions about complementary or alternative therapies for COPD. There is limited evidence about the cost-effectiveness of pulmonary rehabilitation programs (e.g. exercise, education and counselling) for people with COPD. The NCCHTA is currently in the process of commissioning primary research in this area—inviting applications for controlled trials assessing the longer term impact (at least 18 months) of different types of programs in different settings[29]. The results of successful projects would, however, not be available until sometime in 2004.

Audit—Home oxygen (fixed and portable) in Québec

It is recommended that a region by region assessment of current practice for LTOT in Québec be undertaken to better understand details such as: patterns of utilization (i.e. who is receiving LTOT and what proportion of patients are using portable systems); the types of equipment provided and criteria being applied (explicit and implicit) for patient and equipment selection; the extent of public and private provision of services; arrangements for clinical follow-up—including the roles of suppliers, CLSCs and hospital-based services.

Patient education and support

As is the case for other specialized services, there is some evidence that outcomes are improved for patients with chronic diseases, where treatment involves dependence on technological intervention, if the therapy is provided in the context of formal programs for patient education and support [see for example in the case of diabetes, Campbell et al., 1990]. A case-control study of patients receiving long-term home parenteral nutrition therapy

28. Dr. Yves Lacasse, personal communication—October 14, 2003.

29. See NCCHTA listing of Research Priorities—project 01/15 at http://www.ncchta.org/.

reported significantly higher quality of life scores, lower depression scores and a lower incidence of catheter-related infections for patients affiliated with a national patient support and education organization [Smith et al., 2002]. Further research is required regarding the extent to which educational and support mechanisms for COPD patients may be effective in improving compliance with LTOT therapy and smoking cessation—two areas that would positively impact survival for this group of patients.

Secondly, given the evidence that patients are relatively poor at recognizing symptoms of COPD and seeking treatment, more work is needed to understand how best to educate and motivate patients to recognize health problems and seek help earlier.

Physician education

More work is required to identify effective means of educating and updating physicians involved in the diagnosis and care of COPD patients at home, particularly given the evidence that physicians tend to under-diagnose COPD, and as COPD is a growing public health concern.

Quality of life

Although a multitude of standardized instruments exist to measure quality of life in COPD [for example, as reviewed by Lacasse et al., 1997]. Further development would be useful to facilitate routine measurement and monitoring of quality of life for COPD patients on LTOT in clinical practice. Simple, reliable methods are needed to support the collection of routine data on process and outcome attributes of providing LTOT.

Standardized assessment tools

As per the studies by Lock et al. [1991] and Guyatt et al. [2001], further work needs to be undertaken to design simple, standardized assessment tools to support a consistent prescription of LTOT (fixed and portable), in turn contributing to improved capacity to monitor and re-assess patients' compliance and needs for continued therapy.

APPENDIX A

INTERVIEW FRAMEWORK FOR CLINICAL TEAMS

Organisation des services

Quels sont les services offerts ? Comment sont-ils organisés ?

Équipe soignante (composition, nombre)

Processus de prescription

Matériel (accès)

Formation du personnel soignant

Liens avec les services communautaires et les CLSC

Rôles des associations professionnelles

Budget

Rapport annuel ?

Y a-t-il des projets de recherche autour du programme ?

Patients

Critères de sélection des patients (structurés)

Nombre de patients

Utilisation des services (nombre de patients/mois ou année)

Caractéristiques cliniques des patients (âge, sexe, maladies concomitantes, etc.)

Liste d'attente

Groupes de soutien ou d'aide pour les patients/aidants ?

Rôle des patients et des aidants dans le traitement (enseignement)

Résultats

Bénéfices pour les patients : comment sont-ils évalués ?

Préférences et satisfaction des patients (évaluation ?)

Qualité de vie des patients (amélioration, évaluation)

Qualité des soins

Quelles lignes directrices et protocoles de soins sont utilisés ?

Y a-t-il un audit de la qualité (mécanisme, fréquence, portée) ?

Quels types d'informations sont consignées systématiquement ? À qui servent ces informations ?

Innocuité et risques

Quels sont les risques ? Comment sont-ils gérés ?

Responsabilité : Qui est responsable (soins aux patients, accidents, bris de matériel, etc.) ?

Coûts

Prix du matériel (concentrateur, bouteilles, remplissage)

Politiques de remboursement (établissement, patient, assurance, etc.)

Technologie

Quel matériel est fourni ?

Qui possède le matériel ?

Qui est responsable de l'entretien et de la résolution des problèmes techniques ?

Quelles sont les tendances (nouveaux dispositifs ou procédés) ?

Enjeux principaux

Quels sont les principaux enjeux cliniques et organisationnels (barrières, défis, aspects éthiques, motivations) ?

Quels aspects de ces services pourraient être améliorés ?

Quels sont les principaux enjeux en ce qui concerne les patients ?

La demande pour ces services va-t-elle s'accroître ou diminuer ?

Quelles sont les solutions de rechange pour les patients qui ne sont pas admissibles ?

APPENDIX B

SURVEY OF QUÉBEC SUPPLIERS

Agence d'évaluation des technologies et des modes d'intervention en santé **(AETMIS)**
Report on Portable Home Oxygen Therapy

June 2001

QUESTIONS FOR SUPPLIERS OF PORTABLE OXYGEN EQUIPMENT

Thank you very much in advance for taking the time to respond to these questions.

Please be assured that we intend to aggregate the responses in the final report so that individual responses will be confidential. If we feel that specific data or direct quotes might be helpful, we will obtain your permission to include any such material (with appropriate references/credits to the source) in the report.

For convenience—if any of the items below are detailed in other documents, such as a prospectus, annual report, or brochure, please feel free to choose to send these (instead of completing the sections below) and we will be happy to extract the relevant information).

It is intended that you will be able to complete the following in **20-30 minutes**. Please indicate the name and phone number of the person we should contact if it is necessary to clarify or follow-up any of the responses:

Contact name/phone number: _____
Company: _____

Please send responses (on this form or on separate sheets of paper) **by July 31 to:**

Susan Law, Consultant Researcher
AETMIS
2021, avenue Union, bureau 1040
Montréal, Québec H3A 2S9
phone: (514) 873-4097
fax: (514) 873-1369
e-mail: susan.law@mrst.gouv.qc.ca

Questions for Suppliers of Home Oxygen Equipment and Supplies

Organization

How do you describe your organization---e.g. distributor/vendor, manufacturer?

Is home oxygen equipment your primary product?

Where is the Head Office?

Scope of company (provincial, national, international)?

Size of company (e.g. total number of employees)?

Organization in Québec (e.g. number of regions/territories/offices)?

Where is the equipment manufactured?

Who owns the equipment?
Do patients, hospitals, CLSCs purchase or lease portable oxygen therapy equipment and supplies?

Services

What services do you provide for patients?
e.g. provision of equipment, supplies, training, maintenance, refills, home visits
what arrangements are there for emergency back-up (e.g. in a power failure)?

How are the arrangements different for public versus privately insured patients?
e.g. contracts with patients or CLSCs; number of visits

What type of *equipment* for home oxygen therapy is used?
names, models of portable oxygen equipment, gas or liquid.

What services do you provide for professionals (hospital or community)?
e.g. training, supply of equipment, maintenance, repair
what maintenance agreements for equipment are in place (with whom?)

What area does your company serve for home oxygen therapy?
e.g. the province of Québec; Montreal and Québec only; etc.

On what basis do you compete with other suppliers of home oxygen equipment?
e.g. quality of service, price, particular technology, etc.

How are services delivered?
who orders oxygen equipment and decides about changes and need for refills, etc.?
routine number of deliveries *per client per week or month*

What prices do you charge for your services and who pays?
what proportion of contracts with CLSCs, *hospitals and/or patients?*
who decides if there are any patient *charges*
do prices differ amongst types of clients? *(privately insured or not?)*

Patients

How many patients on home oxygen therapy does your company currently serve in Québec?

What proportion of these patients are on portable oxygen therapy?

What underlying conditions do most patients have on oxygen therapy?
Are there patients with other illnesses besides COPD receiving portable oxygen?

How well do you feel that patients cope with the technology of home oxygen therapy?
is it relatively easy for them to adapt? home modifications; psychological support needed? safety concerns?

Are you aware of any waiting lists (at hospitals, CLSCs or within the company) for portable oxygen therapy? If yes, what are the factors limiting access?

Benefits of Portable Oxygen Therapy

From your perspective, what are the benefits to patients of portable oxygen therapy?

Do you feel that the current referral criteria for portable oxygen therapy are appropriate?
yes/no and why

Current Issues

From your perspective, what are the key issues and/or problems with the delivery of portable home oxygen therapy services *in* Québec at the moment?
e.g. access (rural/urban; private insurance/Medicare), trends in utilization, etc.

Do you have suggestions for improvements or change in the system?

What new innovations or trends are emerging for portable oxygen therapy?

Other comments

Please feel free to add any additional comments that you feel would be helpful to our study on portable oxygen therapy.

Please feel free to send any documents/material (e.g. annual reports, newsletters, teaching material, specifications, research) to support your responses to the above.

June 28, 2001

Susan Law, MHSc
Consultant Researcher, AETMIS

Summary—Studies of Clinical and Cost-Effectiveness of Portable Oxygen Therapy in COPD

STUDY	OBJECTIVES	METHODS	RESULTS AND COMMENTS
Clinical Effectiveness of Portable vs. Fixed Therapy			
Vergeret et al., 1989 France	To evaluate the effects of portable oxygen therapy on daily duration of therapy and on daily activities; also to consider respective advantages of gas or liquid oxygen.	Randomized controlled trial. Sample: n=159 (139 males); patients with severe COPD on fixed system of LTOT; able to walk 200m in 12 mins. with portable system. Excluded: patients with portable systems; other severe co-morbidities. Patients randomized to: oxygen concentrator (OC; n=75) vs. OC plus portable gas cylinders (n=51) vs. liquid oxygen (n=33) Patients followed for one year. Used non-validated instruments.	• No significant clinical or functional differences between groups at beginning or throughout trial. • The group with portable systems (gas and liquid) had longer daily duration of therapy (17 hours vs. 14), no difference between gas and liquid systems. • Only 60% of patients with portable systems used them for activities outside the home; 25% never used portable system (this group had gas systems) • Close supervision advised during first 3 months after prescription of portable system to assess use and usefulness.
Comparison of Liquid vs. Compressed Gas Systems			
Andersson et al., 1998 Sweden	To compare effects of liquid oxygen treatment on quality of life and costs in comparison to standard treatment (concentrator plus compressed gas cylinders).	Prospective, randomized multicentre trial. Cost utility analysis. Sample: n=51 patients at home with chronic hypoxaemia (47 had COPD) who were regularly active outside the home. Excluded: patients unable to leave home or unable to use mobile equipment. Patients randomized to: liquid oxygen (n=29) vs. standard treatment (n=22). Patients followed for 6 months. HR-QOL instruments*: SIP, EuroQol	• The SIP indicated improved quality of life after 6 months for the liquid oxygen group; no improvement was found using the SIP for the concentrator group. Changes in quality of life were less clear using the EuroQol. • Average total cost (including health care services plus equipment and oxygen) per patient for 6 months was: US $1,310 for patients receiving LTOT via concentrator plus portable cylinders; US $4,950 for patients using liquid oxygen.

Summary—Studies of Clinical and Cost-Effectiveness of Portable Oxygen Therapy in COPD

STUDY	OBJECTIVES	METHODS	RESULTS AND COMMENTS
Lock et al., 1992 UK	To compare liquid versus gaseous oxygen for portable use.	Randomized controlled trial. Sample: 15 patients with COPD and hypoxemia. Liquid and gaseous oxygen were provided in random order for two eight-week periods; assessments included 6-minute walking test, lung function tests, chronic respiratory disease questionnaires, and diary cards.	▪ Walking distance was not affected by the weight of either system. ▪ Patients used the liquid oxygen more (average 23.5 hours per week) versus gaseous oxygen (average 10 hours per week) ▪ When using liquid oxygen, patients spent 19.5 hours per week out of the house compared to 15.5 hours on gaseous oxygen. ▪ Patients reported that they preferred the liquid oxygen system because the oxygen lasted longer, filling was easier, and the canister was easier to carry.
Utilization of Portable Systems			
Crockett et al., 1996 Australia	To document quality of life and survival following prescription of home oxygen therapy. (reporting the results of first 6 months of longitudinal study)	Prospective study. Sample: n=57 patients (29 males, 28 females) < 80 yrs referred for home oxygen therapy with severe chronic airflow limitation. Excluded: 18 patients unable to complete assessment, refusals, limited English, no exclusions for co-mobidities. Oxygen therapy either concentrator with portable cylinder or liquid system. Follow-up was at 3 and 6 months after initiation of home oxygen therapy. HR-QOL instruments*: NHP, CRDQ, QOLTH, LSI	▪ 51 patients had concentrator; 6 had liquid gas, all had portable equipment. ▪ No correlation at baseline between physiological factors and quality of life ▪ Women showed some improvement in quality of life; men—results were unclear. ▪ 8 patients (14%) had continued to smoke ▪ Median survival: 21.9 months for men; 29.0 months for women; good compliance - >19 hrs/day (mean), prescription was 20.9 hrs/day (mean) ▪ No analysis by type of system.

Summary—Studies of Clinical and Cost-Effectiveness of Portable Oxygen Therapy in COPD

STUDY	OBJECTIVES	METHODS	RESULTS AND COMMENTS
Guyatt et al., 2000 Ontario, Canada	To assess whether recipients of the Ontario Home Oxygen Program meet program criteria	Cross-sectional survey Sample: n=237 patients receiving home oxygen in the Ontario Home Oxygen Program (HOP), majority with COPD Measured spirometry, use of oxygen and degree of activity, patient experience with dyspnea	▪ 40.5% patients did not meet criteria for home oxygen therapy; prescribed flow rates were higher than expected; 10.3% continued to smoke ▪ Specialists and primary physicians had similar rates of appropriate prescribing ▪ A high proportion of patients, whether they met the criteria or not, perceived "a very important health benefit" from oxygen, suggesting important placebo effect in subjective benefits of LTOT ▪ Authors suggest: HOP could realize a 30% budget reduction ($16.5 million) if home oxygen was denied to those not eligible as per established criteria, and recommend more stringent follow-up arrangements ▪ Authors reported that: "approximately one third of the patients were largely restricted to their homes, one third were relatively mobile, and one third spent a large amount of time outside the home".
Pépin et al., 1996 France	To assess daily use of LTOT and identify factors associated with effective use of LTOT	Prospective study Sample: n=930 patients with COPD and hypoxemia, representing 10% of patients on LTOT chosen at random from each of 14 regional registers Daily use of oxygen measured over 3 months Survey questionnaire completed by independent investigator, prescribing physicians asked about duration and type of oxygen prescribed	▪ LTOT was prescribed on average for 16 ± 3 h/day ▪ 45% patients achieved 15 h/day or more of LTOT ▪ 271/893 (30%) of patients with concentrators had portable systems prescribed ▪ Patients' actual use of portable systems was less than they claimed ▪ 4% (38 patients) used oxygen outside the home; 37 of these patients had liquid systems ▪ Factors associated with increased effective use of LTOT: initial prescription over 15 h/day; supplementary patient education; cessation of smoking; use of oxygen in all domestic situations; absence of side effects

Summary—Studies of Clinical and Cost-Effectiveness of Portable Oxygen Therapy in COPD

STUDY	OBJECTIVES	METHODS	RESULTS AND COMMENTS
Ström et al., 1990 Sweden	To assess quality of life and ability to cope with therapy for patients prescribed LTOT using either concentrators or gas cylinders.	Cross-sectional survey. Sample: n=41 patients on home oxygen therapy (31 with COPD) living in two counties where different mode of oxygen supply is used in each county; n=23 using concentrators, n=18 using gas cylinders. Mean age: 69 years (range 49-85). HR-QOL instruments*: SIP. Details of oxygen therapy obtained from Swedish Oxygen Register.	• quality of life was impaired in both groups; no significant difference between groups; oxygen therapy improved sense of well-being in all but one patient; • patients found concentrators easier and safer to handle than cylinders; operating costs were twice as high for cylinders compared to concentrators. • use of portable oxygen was higher in the concentrator group (21/23) vs. gas cylinder group (13/18). • the majority of patients using concentrators required help to handle portable equipment. • Authors note that the difficulty experienced in handling the portable cylinders "prevent many patients from participating in outdoor ambulation."
Development of Guidelines for Prescribing			
Brambilla et al., 1985 Italy	To assess whether the additional burden of a portable liquid system outweighs the advantages of supplemental oxygen.	Cohort study. Sample: n=12 hypoxemic patients with COPD; analysis undertaken on 8 patients with significant level of desaturation (greater than 25 units in 5 mins.) on standard exercise test. Patients performed exercise test: on room air; with liquid oxygen on floor; carrying liquid oxygen on shoulder (weight of system=4.2 kg.); oxygen flow was 3 L/min. Measured: metabolic cost of carrying portable system.	• The additional load of the portable system did not outweigh the benefits of supplemental oxygen. • Oxygen desaturation was corrected by oxygen. • Authors suggest that oxygen-supported exercise should improve activities of daily living and physical condition of hypoxemic patients.
Guyatt et al., 2001 Ontario, Canada	To examine protocols for minimizing hypoxaemia with day to day activities and exercise.	Cross-sectional study. Sample: n=74 COPD patients with prescription for oxygen at rest or exercise, recruited from repiratory rehab programs and from Ontario HOP; patients had demonstrated hypoxaemia on at least one occasion.	• proposed standardized, simple protocols for the home or hospital assessment of patients to prescribe LTOT.

Summary—Studies of Clinical and Cost-Effectiveness of Portable Oxygen Therapy in COPD

STUDY	OBJECTIVES	METHODS	RESULTS AND COMMENTS
Lock et al. 1991 UK	To assess use of portable oxygen to develop guidelines for prescribing portable oxygen therapy.	Retrospective review. Sample: 50 patients prescribed portable oxygen at London Chest Hospital.	• Observed placebo improvement using an air cylinder. • 14/50 patients used portable system frequently; only 8 used it outside more than 5 times per week. • Authors recommended standardized portable oxygen assessments based on a series of 6-min walks; improvements of 10% in walking distance or breathlessness score would indicate patient should be offered a portable cylinder. • Only 29 of 50 patients would have been prescribed portable therapy using the above criteria.
McKeon et al. 1988 Australia	To determine predictive factors for performance and benefit of supplemental oxygen for patients with COPD during exercise.	Randomized, double-blind, placebo-controlled trial. Sample: 21 patients with COPD, 6 on LTOT; some patients were hypoxemic; all with exertional dyspnea. Patients performed 3 exercise tests on (in random order): room air; portable cylinder with oxygen; portable cylinder with compressed air.	• Using portable oxygen, patients walked further, were less breathless, and had a lower heart rate compared to room air and compressed air. • Benefit from oxygen could not be predicted from resting pulmonary tests or blood gases, or extent of desaturation on exercise. • No placebo effect found. • Authors concluded that prescription of portable oxygen should be preceded by formal exercise testing.
Economic Analysis			
Pelletier-Fleury et al. 1997 France	To compare the cost-effectiveness of home oxygen therapy under not-for-profit (NP) versus for-profit (FP) sectors.	Retrospective economic analysis. Clinical and administrative data obtained from health insurance program for self-employed professionals (CANAM).	• Survival was similar in both groups. • Costs for home oxygen therapy were lower in the NP group, due to higher use of concentrators (versus gas cylinders), costs varied as per use of portable systems. • Flat rates are set in the NP sector by type of system (concentrator: $US 7.71 per day; gas: $US 14.93; or liquid: $US 18.67), with or without portable systems; rates in the FP sector are set, regardless of the system, either without portable ($US 10.89 per day) or with portable system ($US 19.41 per day); 1994 prices. • A small proportion in each group had portable systems: 8/30 in the NP group, 3/31 in the FP group.

*HR-QOL (health-related quality of life instruments).
NHP: Nottingham Health Profile; CRDQ: Chronic Respiratory Disease Questionnaire; QOLTH: Quality of Life Thermometer; LSI: Life Satisfaction Index; SIP: Sickness Impact Profile.

APPENDIX D

UK DOMICILIARY OXYGEN RECORD (DOR)— AMBULATORY ASSESSMENT FORM

DOMICILIARY OXYGEN RECORD FORM: Ambulatory oxygen therapy assessment

Patient name

Address

GP

Address

Telephone

Consultant

Address

Telephone

Respiratory nurse contact

Telephone

Diagnosis

Daily estimated use (hours)

Chronic obstructive pulmonary disease ❑ Cystic fibrosis ❑

Interstitial lung disease ❑ Pulmonary hypertension ❑

Neuromuscular/chest wall disease ❑ Pulmonary/sleeping disorders ❑

Heart failure ❑ Other (specify)

	Date	SaO_2 at rest	Type of exercise	SaO_2 during exercise	Recovery time
Assessment on air					
Assessment on oxygen (... litres)					

	Date	SaO_2 at rest	Type of exercise	PaO_2	$PaCO_2$
Blood gas on					

Prescription for ambulatory oxygen therapy

Oxygen delivery system — Litres/min — Hours/day

Device — Other additional devices (specify)

Nasal ❑

Cannula ❑

Prescriber's name — Date

Signature — Designation

Appendix: Domiciliary oxygen record forms

APPENDIX E

SOCIETE SUISSE DE PNEUMOLOGIE (SSP) PRESCRIPTION FORM (SWITZERLAND)

Prescription pour oxygénothérapie au long cours avec
concentrateur d'oxygène ☐ ou *oxygène liquide* ☐ 2

Selon les lignes directrices de la Société suisse de pneumologie (SSP)
et les tableaux Lima (Liste des moyens et appareils)
Les indications en italique sont *obligatoires en cas de prescription d'oxygène liquide.*

A) INFORMATIONS GENERALES (s.v.p. remplir complètement)

Nom, Prénom:
Adresse:
NPA / Lieu: Canton:
Téléphone:
Profession:
Caisse-maladie:

Sexe: M F
Date de naissance:
N° ID:
Assurance invalidité: oui non
CM-N° membre:
Section:

B) DIAGNOSTIC PRINCIPAL Code: ;__; (s.v.p. reporter le code selon la liste ci-dessous)

10 Maladies pulmonaires obstructives
11 Asthme
12 Maladies pulmonaires restrictives
13 Troubles respiratoires du sommeil
14 Troisième cause éventuelle

40 Maladies vasculaires (hypertension pulmonaire)
50 Maladies cardiaques
(oedème pulmonaire, malformation cardiaque, insuffisance cardiaque)
60 Autres maladies
(cancer, mucoviscidose, hypoventilation alvéolaire, fibrose pulmonaire)
90 Autres:

C) SELON PRESCRIPTIONS SSP + LIMA, RESULTATS D'EXAMENS OBLIGATOIRES

Fonctions pulmonaires: Date: CV: % valeur théorique FEV1: % valeur théorique
Labo: Hémoglobine: g% Hématocrite: %
Gaz sanguins: air kPa Date PaO2 PaCO2 SaO2%
sous oxygénothérapie (débit)
au repos sans O2
après 1' 30 min. O2
à la limite subjective sans O2
avec O2

Exploration du volet pulmonaire physique: oui non

D) PRESCRIPTION POUR CONCENTRATEUR D'OXYGENE ☐ OU *OXYGENE LIQUIDE* ☐

Durée: Débit O2: au repos: l/min test d'effort: l/min
Débit: *Mobilité hors du domicile:* heures/jour
Mode d'administration:
Lunettes O2 Autres
Sonde nasale/masque % oxygène Longueur: Début du traitement:

E) MEDICINS

1 Médecin prescripteur: Signature
Date de la visite clinique: + Timbre
Date de la prescription: incl. N° du concordat:
2 Médecin traitant:
3 Le pneumologue responsable:

F) DECISION DE L'ASSUREUR-MALADIE: accordé refusé (motivation jointe)

Timbre / Signature:

Première prescription Renouvellement de prescription

VEUILLEZ RENVOYER LA PRESCRIPTION
DUMENT REMPLIE A:
(Cachet de la ligne pneumologie)

→ Limitations Lima (voir au verso)

Limitations pour l'oxygénothérapie au long cours avec concentrateur (selon Lima) :

Manque persistant d'oxygène en cas de maladie chronique des poumons et des voies respiratoires dûment diagnostiquée. La prescription se fonde sur les lignes directrices de la Société suisse de pneumologie (état au 20.09.1996). Le remboursement nécessite une garantie de paiement préalable établie par l'assureur. Il est lié aux conditions suivantes:

- Fixation de l'indication et ordonnance par un pneumologue FMH.
- Réalisation d'analyses répétées des gaz sanguins au cours du dernier trimestre qui précède le dépôt de la demande, exécutées au repos dans des conditions cliniquement stables, avec une pression partielle constante pO_2 inférieure à 55 mmHg ou située entre 55 et 60 mmHg en cas de signes objectifs d'un cœur pulmonaire et/ou de polyglobulie sévère.
- On dispose des résultats d'un examen fonctionnel approfondi effectué durant le mois qui précède la demande.
- L'autorisation de remboursement est valable 12 mois au maximum.
- En cas de demande de renouvellement de la garantie de remboursement, l'indication et les conditions de traitement seront examinées comme s'il s'agissait d'une première demande.
- Le manque de collaboration du patient constitue aussi un motif de refus d'octroi de l'autorisation. Si une nouvelle demande de garantie de remboursement est présentée après un tel refus, un avis positif du médecin qui pose l'indication sera remis à l'assureur en ce qui concerne la collaboration du patient.

Les conditions suivantes s'ajoutent pour l'oxygénothérapie avec oxygène liquide :

- *Mobilité avec sortie quotidienne de plusieurs heures à l'extérieur du domicile de l'assuré. - Examen clinique, des mesures de l'oxygène (analyses des gaz sanguins) datant du mois précédant la demande et effectuées sous test d'effort standardisé avec et sans apport d'oxygène ainsi qu'une évaluation de la compliance thérapeutique sont disponibles et prouvent que l'apport en oxygène supplémentaire est bénéfique pour obtenir la mobilité nécessaire.*
- *Durée maximale d'autorisation : 6 mois.*
- *Si, en raison de changements de situation, les conditions de mobilité mentionnées ne sont plus réunies, la prise en charge des coûts n'est plus garantie même si l'autorisation de six mois n'est pas arrivée à échéance.*
- *Un médecin-conseil de l'assureur doit avoir autorisé la thérapie.*

APPENDIX F

HMR FORM FOR PORTABLE OXYGEN THERAPY

HMR Hôpital Maisonneuve-Rosemont
Centre affilié à l'Université de Montréal

Service régional de soins à domicile (mpc)

VÉRIFICATION DE L'ADMISSIBILITÉ POUR L'OXYGÉNOTHÉRAPIE DE DÉAMBULATION

☐ 1ère demande ☐ 2ième demande ☐ 3ième demande

1. CRITÈRES D'ADMISSIBILITÉ

L'USAGER EST ADMISSIBLE AU PROGRAMME D'OXYGÉNOTHÉRAPIE POUR HANDICAPÉES	OUI ☐	NON ☐
L'USAGER N'A PAS D'AUTRE AGENT PAYEUR POUR L'OXYGÈNE DE DÉAMBULATION	OUI ☐	NON ☐
L'USAGER EST EN ATTENTE DE GREFFE PULMONAIRE	OUI ☐	NON ☐
L'USAGER PARTICIPE À UN PROGRAMME RECONNU DE RÉADAPTATION PULMONAIRE AVEC UNE HYPOXÉMIE À L'EFFORT SEULEMENT (PO2<50 mmHg)	OUI ☐	NON ☐
L'USAGER A UNE HYPOXÉMIE RELATIVE QUI RISQUE DE S'AGGRAVER À L'EFFORT (VOIR TEST DE SATURATION À L'EFFORT)	OUI ☐	NON ☐
L'USAGER A DES SORTIES FAMILIALES, SOCIALES OU PROFESSIONNELLES	OUI ☐	NON ☐
L'USAGER A LA CAPACITÉ PHYSIQUE DE SORTIR	OUI ☐	NON ☐
L'USAGER DÉSIRE ET ACCEPTE D'UTILISER TEL QUE PRESCRIT L'OXYGÈNE DE DÉAMBULATION	OUI ☐	NON ☐

SIGNATURE DE L'INTERVENANT : _____
DATE : _____

RÉSULTAT DE TEST DE SATURATION À L'EFFORT

_____

_____

_____

_____

ADMINISTRATION SEULEMENT

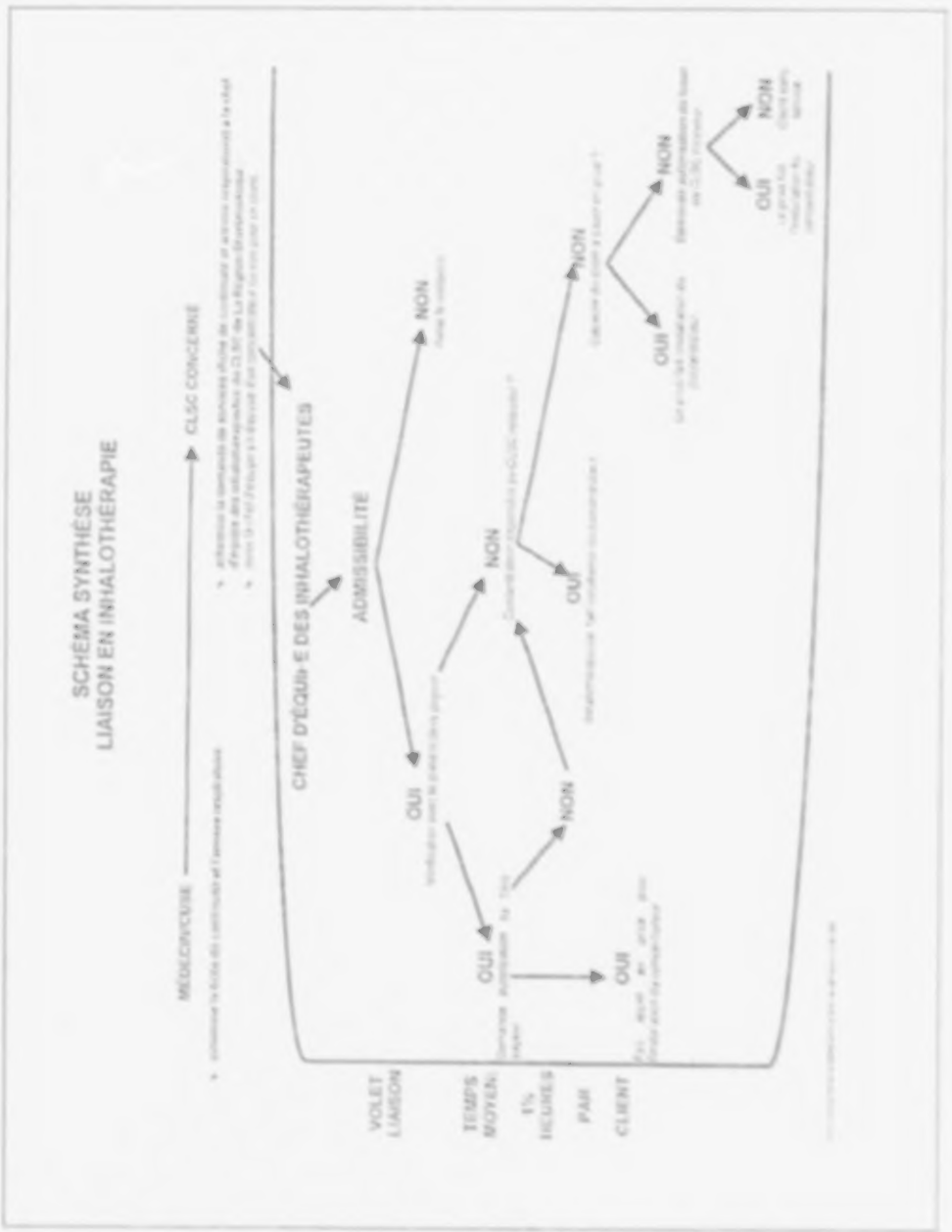
Demande oxygénothérapie : ☐ faite le _____ ☐ autorisée le _____ ☐ refusée le _____
de déambulation

Nom à l'ordre _____ Dr/Dre _____

Pour vous, pour la vie

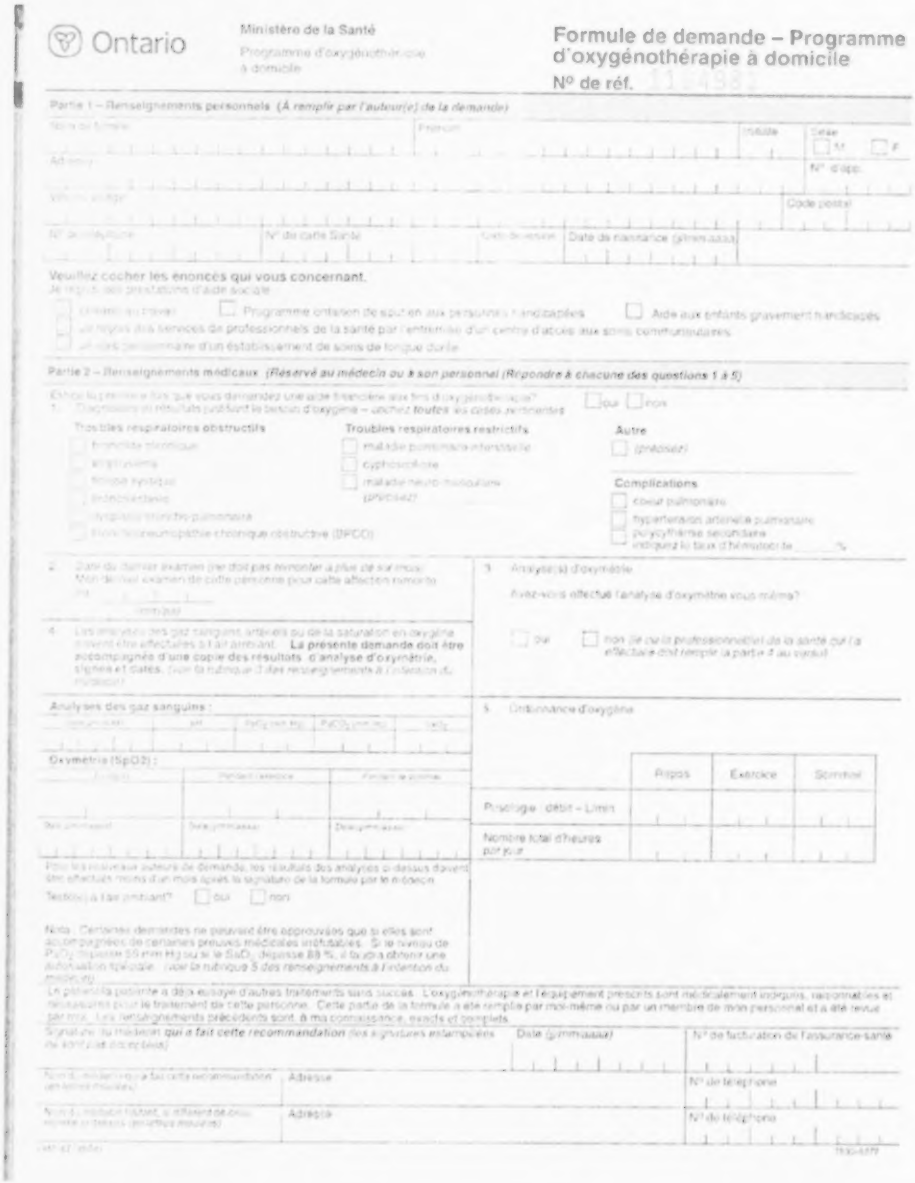
APPENDIX G

DECISION ALGORITHM—COVERAGE FOR HOME LTOT (SHERBROOKE AREA)



APPENDIX H

ONTARIO HOME OXYGEN PROGRAM APPLICATION FORM



Ontario

Ministère de la Santé

Programme d'oxygénothérapie à domicile

Formule de demande – Programme d'oxygénothérapie à domicile

Nº de réf.

Partie 1 – Renseignements personnels *(À remplir par l'auteur(e) de la demande)*

Nom de famille | Prénom | Initiale | Sexe ☐ M ☐ F

Adresse | Nº d'app.

Ville ou village | Code postal

Nº de téléphone | Nº de carte Santé | Date de naissance (jj/mm/aaaa)

Veuillez cocher les énoncés qui vous concernent.

Je reçois des prestations d'aide sociale

☐ Ontario au travail ☐ Programme ontarien de soutien aux personnes handicapées ☐ Aide aux enfants gravement handicapés

☐ Je reçois des services de professionnels de la santé par l'entremise d'un centre d'accès aux soins communautaires

☐ Je vais personnellement d'un établissement de soins de longue durée

Partie 2 – Renseignements médicaux *(Réservé au médecin ou à son personnel (Répondre à chacune des questions 1 à 5)*

Est-ce la première fois que vous demandez une aide financière aux fins d'oxygénothérapie? ☐ oui ☐ non

1. Diagnostic(s) et résultats justifiant le besoin d'oxygène – *cochez toutes les cases pertinentes*

Troubles respiratoires obstructifs

☐ bronchite chronique
☐ emphysème
☐ fibrose kystique
☐ bronchectasie
☐ hypertension pulmonaire
☐ maladie pulmonaire obstructive chronique (BPCO)

Troubles respiratoires restrictifs

☐ maladie pulmonaire interstitielle
☐ cyphoscoliose
☐ maladie neuro-musculaire (préciser)

Autre

☐ (préciser)

Complications

☐ cœur pulmonaire
☐ hypertension artérielle pulmonaire
☐ polycythémie secondaire
indiquez le taux d'hématocrite ____%

2. Date du dernier examen (ne doit pas remonter à plus de six mois)
Mon dernier examen de cette personne pour cette affection remonte au
(mm/aaaa)

3. Analyse(s) d'oxymétrie

Avez-vous effectué l'analyse d'oxymétrie vous-même?

☐ oui ☐ non *(le ou la professionnel(le) de la santé qui l'a effectuée doit remplir la partie 4 au verso)*

4. Les analyses des gaz sanguins artériels ou de la saturation en oxygène doivent être effectuées à l'air ambiant. **La présente demande doit être accompagnée d'une copie des résultats d'analyse d'oxymétrie, signés et datés.** *(voir la rubrique 3 des renseignements à l'intention du médecin)*

Analyses des gaz sanguins :

Température | pH | PaO_2 (mm Hg) | $PaCO_2$ (mm Hg) | HCO_3

Oxymétrie (SpO_2) :

Pendant l'exercice | Pendant le sommeil

Désaturation | Désaturation | Désaturation

Pour les nouveaux auteurs de demande, les résultats des analyses ci-dessus doivent être effectués moins d'un mois après la signature de la formule par le médecin.

Testé(e) à l'air ambiant? ☐ oui ☐ non

Nota : Certaines demandes ne pourront être approuvées que si elles sont accompagnées de certaines preuves médicales irréfutables. Si le niveau de PaO_2 diminue à 55 mm Hg ou si le SaO_2 diminue à 88 %, il faudra obtenir une autorisation spéciale. *(voir la rubrique 5 des renseignements à l'intention du médecin)*

5. Ordonnance d'oxygène

	Repos	Exercice	Sommeil
Physiologie : débit – L/min			
Nombre total d'heures par jour			

Le patient a présenté à deux reprises d'autres traitements sans succès. L'oxygénothérapie et l'équipement prescrits sont médicalement indiqués, raisonnables et nécessaires pour le traitement de cette personne. Cette partie de la formule a été remplie par moi-même ou par un membre de mon personnel et a été revue par moi. Les renseignements précédents sont, à ma connaissance, exacts et complets.

Signature du médecin *qui a fait cette recommandation* (les signatures estampillées ne sont pas acceptées) | Date (jj/mm/aaaa) | Nº de facturation de l'assurance-santé

Nom du médecin qui a fait cette recommandation (en lettres moulées) | Adresse | Nº de téléphone

Nom du médecin traitant, si différent de celui qui a fait la recommandation (en lettres moulées) | Adresse | Nº de téléphone

(voir au verso)

7530-6377

Partie 1 – Équipement d'oxygénothérapie à fournir *(À remplir par le médecin ou la [illegible])*

Description du système d'oxygénothérapie	N° de catalogue du POD	Quantité/mois	Coût total
	Coût mensuel total		
	Moins le montant mensuel payé par l'auteur(e) de la demande		
	Montant facturé au POD		

Note : Le vendeur/la vendeuse doit indiquer le montant total qu'il en coûte à l'auteur(e) de la demande et, le cas échéant, le montant payé par l'auteur(e) de la demande.

Date de l'installation *(j/mm/aaaa)*

(Le vendeur/la vendeuse doit remplir la partie ci-dessous, sans quoi la demande de règlement ne sera pas approuvée.)

Nom du vendeur/de la vendeuse

N° d'inscription du vendeur/de la vendeuse

Adresse du vendeur/de la vendeuse

N° de téléphone

J'atteste par la présente que ces renseignements sont, à ma connaissance, exacts et complets et que l'équipement d'oxygénothérapie décrit a été fourni à l'auteur(e) de la demande par

Signature du vendeur/de la vendeuse

Date *(j/mm/aa)*

Partie 2 – Analyse d'oxymétrie *(À remplir par le professionnel/la professionnelle de la santé réglementé(e) qui a effectué l'analyse d'oxymétrie)*

Nom de famille

Prénom

Profession

Je confirme avoir effectué, en toute compétence possible, une analyse d'oxymétrie pour

(nom de l'auteur(e) de la demande)

le *(j/mm/aaaa)*

et que les résultats fournis sont indiqués à la partie 2.

N° de téléphone au travail

N° d'inscription à l'ordre professionnel/de certificat

Signature

Date (j/mm/aaaa)

Le ministère de la Santé se réserve le droit de confirmer que le professionnel/la professionnelle de la santé nommé(e) ci-dessus est membre en règle de l'ordre professionnel approprié.

Partie 3 – Désagrément de responsabilité *(À remplir par l'auteur(e) de la demande ou son représentant/sa représentante et par le/la professionnel(le) de la santé)*

Cette personne fume-t-elle?
☐ non ☐ oui

Y a-t-il des fumeurs au domicile de cette personne?
☐ non ☐ oui

Le médecin de l'auteur(e) de la demande a-t-il été informé?
☐ non ☐ oui

L'auteur(e) de la demande a-t-il/elle accepté de participer à un programme d'abandon de tabagisme? ☐ non ☐ oui

Si l'auteur(e) de la demande fume ou s'il y a d'autres fumeurs au domicile de cette personne, l'auteur(e) de la demande ou son représentant/sa représentante doit signer la déclaration suivante :

Je soussigné(e), au nom de mes héritiers et ayants droit, dégage Sa Majesté du chef de l'Ontario, telle que représentée par la/la ministre de la Santé, ainsi que ses employés et représentants, de toute responsabilité à l'égard des dommages ou pertes que peut entraîner le fait de fumer et d'utiliser en même temps de l'oxygène.

Rappelez-vous. Fumer est dangereux pour la santé.

Signature de l'auteur(e) de la demande ou de son représentant/sa représentante *(le représentant/la représentante doit indiquer son lien de parenté)*

Date *(j/mm/aaaa)*

Partie 4 – Déclaration à remplir par l'auteur(e) de la demande *(À remplir par l'auteur(e) de la demande ou son représentant/sa représentante)*

J'atteste, par la présente, résider en Ontario et avoir besoin de l'oxygène et de l'équipement prescrits sur cette formule. Je ne suis pas hospitalisé(e) dans un hôpital de soins actifs ni dans un hôpital de soins aux malades chroniques. Je ne suis admissible à aucune aide financière pour de l'oxygène versée aux clients de la Commission de la sécurité professionnelle et de l'assurance contre les accidents du travail ou à ceux du ministère des Anciens combattants classés «groupe A». J'atteste que les renseignements contenus dans cette formule sont, à ma connaissance, véridiques, exacts et complets. Je connais les critères d'admissibilité au POD et je suis admissible à une aide financière. J'autorise la divulgation des renseignements ci-dessus au ministère de la Santé, au conseiller/à la conseillère médical(e) du POD, ainsi qu'à ma compagnie d'assurance.

Je suis libre de m'adresser à n'importe quels vendeurs d'oxygène de ma communauté inscrits au POD et dont je peux obtenir l'adresse en communiquant directement avec le personnel du Programme d'oxygénothérapie à domicile.

Je consens à la collecte, par les vendeurs d'oxygène du POD au nom du ministère de la Santé, des renseignements concernant l'identité, l'adresse, le numéro de carte Santé et le numéro de demande d'oxygène de l'auteur(e) de la demande, si le ministère de la Santé a besoin de ces renseignements pour traiter la présente demande de règlement et les factures qui s'y rapportent.

Je consens à ce que la Direction des appareils et accessoires fonctionnels recueille des renseignements médicaux ou autres et les communique à la Commission de la sécurité professionnelle et de l'assurance contre les accidents du travail (commission) et à ce que la commission recueille de tels renseignements et les communique à la Direction des appareils et accessoires fonctionnels, afin de déterminer mon admissibilité à une aide financière de la Direction des appareils et accessoires fonctionnels. J'autorise également le ministère de la Santé à obtenir du ministère de la Consommation et du Commerce (MCC) des renseignements obtenus par MCC en vertu de la *Loi sur les statistiques de l'état civil* dans le but de confirmer la fin de mon admissibilité aux prestations du Programme d'oxygénothérapie à domicile et de divulguer ce genre de renseignements aux vendeurs d'oxygène inscrits au POD pour qu'ils puissent soumettre une demande et les factures connexes.

Signature de l'auteur(e) de la demande, de son père/sa mère, ou de son représentant/sa représentante

Date *(j/mm/aaaa)*

La collecte des renseignements demandés dans cette formule, ainsi que des renseignements sur l'identité, l'adresse, le numéro de carte Santé et le numéro de demande d'oxygène de l'auteur(e) de la demande demandés par le vendeur/la vendeuse au nom du ministère de la Santé relativement à la présente demande de règlement, est autorisée en vertu des paragraphes 6 (1) et 8 (2) de la *Loi sur le ministère de la Santé*, L.R.O. 1990, chap. M.26, afin de déterminer l'admissibilité d'une personne à une aide financière dans le cadre du Programme d'appareils et accessoires fonctionnels, 5700, rue Yonge, North York (Ontario) M2M 4K5, tél. : (416) 327-8804; sans frais : 1 800 268-6021; télécopieur : (416) 327-8188.

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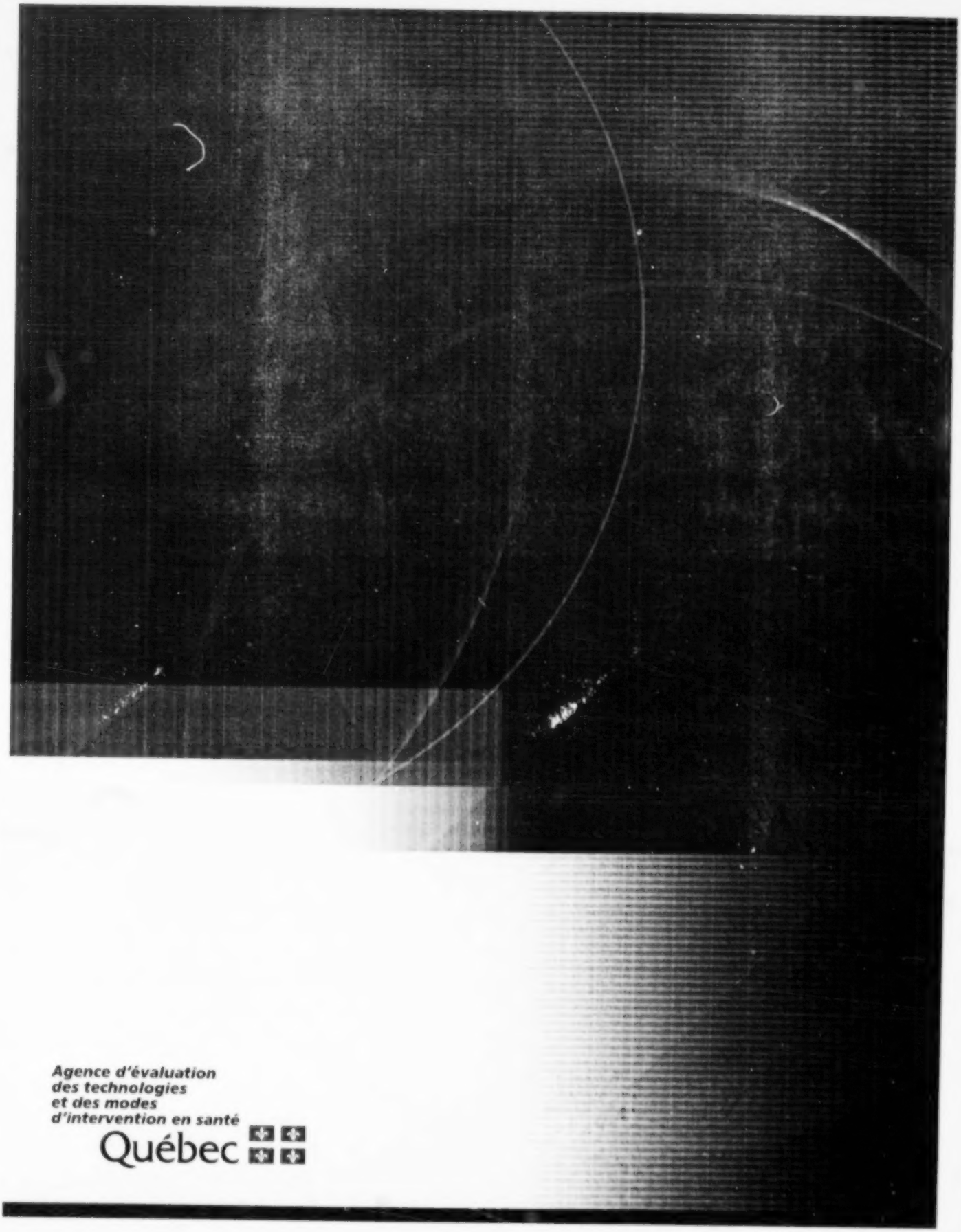

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